

A Phenomenological Analysis of Chronic Pain Self-Management

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Abstract

Self-management is a poorly understood concept from both the academic and patient perspectives. Within the literature it is known as a vague concept which is often mistaken for other terms such as self-care and self-help. The ambiguity surrounding self-management in academia is then transferred to patients through their physicians. Living with a debilitating, invisible condition, such as chronic pain, can force patients to self-manage their conditions. This study set out to not only to define this concept and those related to it, but also to understand what meanings persons with chronic pain ascribe to their self-management. A literature search as well as qualitative interviews were conducted to explore, with more depth, the meanings that participants associate with the phenomenon of self-managing their chronic pain. Five themes emerged from the analysis of interviews: Doctors, Getting Through the Day, Being Limited, My Hidden Burden, and What's Next. Chronic pain proved to be a controlling factor in the lives and decisions of all participants. Overall the self-management behaviours that participants found the most useful, other than medication, were relaxing behaviours that reminded them of their childhood and families.

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Chapter 1: Introduction

Self-management has become an increasingly popular concept over the last 10 years, with three times as many articles published in 2018 (3563), compared to 2008 (1141) (“Web of Science [v.5.30] - All Databases Result Analysis Self-Management,” n.d.). It is used in interventions for a myriad of conditions from mental health (Druss et al., 2010), to diabetes (Wu et al., 2017), asthma (Pinnock et al., 2015), knee osteoarthritis (Morden, Jinks, & Bie Nio Ong, 2011), chronic pain (Burns et al., 2015), PTSD (Possemato et al., 2015), and many more. Self-management interventions have been reported to improve self-efficacy, decrease depression, improve one’s energy, quality of life, and overall, decreases the amount of non-emergent hospitalizations in a variety of populations (Brady et al., 2013; Ory et al., 2013; Zwerink et al., 2014). Self-management, however, is a difficult concept to describe and has many contradicting definitions associated with it (Hutting, Richardson, & Johnston, 2016; Randall & Neubeck, 2016; Winkley et al., 2016). Throughout the literature, it is used both as a synonym for other terms such as self-help or self-care, and is also described as different to these same concepts entirely (Richard & Shea, 2011b; Richards, 2004). There are no standard definitions for these concepts, and they are often described as vague and ambiguous, or they demonstrate blatant discrepancies from one definition to another (Richards, 2004; Winkley et al., 2016). Understanding these concepts and their relationships to one another can provide specificity for academics and physicians alike. Creating plain language definitions can bridge the gap between researchers, doctors and patients, to ensure that every patient is receiving personalized care that they are able to comprehend. To understand what self-management and its associated concepts truly mean, a comprehensive literature search and document analysis needs to be conducted to derive commonalities for these definitions and understand their relationships to one another.

Furthermore, self-management needs to be further understood from the patient perspective. Living with a crippling, invisible condition can force patients to self-manage their conditions. As chronic pain is often a complex, fluctuating and invisible problem, it acts as the perfect avenue through which to investigate self-management (Campbell & Guy, 2007; Snelgrove, Edwards, & Lioffi, 2013).

Chronic pain is an unpredictable, life-long fluctuating embodied state with severe consequences to both the individual experiencing the pain, and those surrounding them (Kowal, Wilson, McWilliams, Péloquin, & Duong, 2012; Osborn & Smith, 1998; Snelgrove et al., 2013). As diagnoses are often difficult to make, many patients feel that they are not taken seriously, describing accusations from their physicians of psychosomatic pain that is ‘all in their heads’ (Campbell & Guy, 2007; Larun & Malterud, 2007; Wendell, 1996). Alternatively, if a patient is believed, they are often treated with opioids, which physicians report prominent levels of uncertainty towards prescribing. Furthermore, these opioids are accompanied by unwanted and harmful side effects for the patient (Fields, 2011; Webster et al., 2017). Medical students also reported that they received little training on how to properly treat and diagnose pain (Fields, 2011; Webster et al., 2017). Therefore, it is not difficult to imagine that patients’ experiences with health care, regarding their pain are typically negative, resulting in feelings of frustration, anger, despair, shame, helplessness, and social isolation (Crowe et al., 2010; Larun & Malterud, 2007; Morden, Jinks, & Ong, 2014; Snelgrove & Lioffi, 2013).

As neither chronic pain, nor self-management behaviours of chronic pain are well understood within the literature, gaining an understanding of these experiences through an in-depth concept analysis is crucial to fill the gaps. While to understand the personal aspect of self-management, as an individual action that differs amongst persons, it is important to generate rich

and deep descriptions from patients themselves in order to discover the complex efforts people engage in to manage their chronic pain (Creswell, 2013). The purpose of this phenomenological study was to describe and understand the meanings that persons in Ontario ascribe to their chronic pain self-management. By virtue of my program location, the informants are based in the Niagara region. This research explored the meanings that participants associate with the phenomenon of self-managing chronic pain, which fill in gaps within the literature and further the understanding of both self-management and chronic pain. Transcendental descriptive phenomenology was used in the service of further disclosing the embodied knowledge of this phenomenon, which may, in turn, affect the future of chronic pain self-management. The main research questions were as follows:

1. What is the operational definition of self-management and its associated terms in relation to chronic pain in applied health science?
2. What meanings do persons in Ontario ascribe to their chronic pain self-management?
3. What are the similarities and differences between the definitions of self-management within the literature and patient perceptions of self-management?

Design features

To best address these research questions, qualitative research, namely transcendental descriptive phenomenology was utilized. A social constructivist framework was adopted by the researcher and utilized throughout the semi-structured interviews. Following the data collection phase, the researcher conducted multi-level analyses of interview transcripts following the

method of Amadeo Giorgi (2009). For more information on the design of this study see Chapter 3: Methods.

Role of the Researcher/Reflexivity

The term ‘chronic’ in relation to a person, refers to something persisting and lasting a long period of time (Oxford Dictionary). Chronic pain, however is an unpredictable, life-long fluctuating condition with severe consequences to both participants and those surrounding them (Campbell & Guy, 2007; Crowe et al., 2010; Larun & Malterud, 2007; Morden et al., 2011; Osborn & Smith, 1998; Snelgrove & Lioffi, 2013). The unpredictable nature of chronic pain and the individualistic behaviours of self-management will result in many different narratives from participants. To prepare myself as a researcher, I have bridled my own experiences with chronic pain. Richardson (1994) states that researchers must not only be aware of their presence during interviews with participants, but also throughout their writing (Creswell, 2013). I, as the principal student investigator, do not have extensive personal experience with chronic pain, however, I have seen it first hand. I have seen it transform a person and destroy them. I have seen the battle that they faced and the negotiations they would make with their body to try and manage it. I have seen the care they are provided, the care that they are denied, and all the choices that they must actively make in a day in order to just make it to the end.

I have never experienced anything quite like that first hand. My closest interaction with this type of pain was a displaced vertebra that rendered me incapable of turning my head fully and caused severe migraines. Unlike with cases of chronic pain, my problem was easily diagnosed once I sought out medical attention, and I was referred to a physiotherapist who began

my treatment. Similarly, however, to the chronic pain literature, it took many months of me rationalizing to myself that the pain was nothing, and that it wasn't important enough to warrant a consultation with a busy practitioner. I found myself unable to drive because I didn't feel safe not being able to look to see my blind spots or if other vehicles were approaching. Some small daily tasks became difficult and I altered my choices around my malfunctioning body part. I found that people around me didn't seem to care about my pain or that I was having a severe head wrenching migraine and I needed to go sit down in a dark room. They wanted everything to operate as it always had. While my issue was minor, I began seeing relationships strain and discovered that no one truly cared, or understood, that I was going to have to manage my migraines and pain alone. I am absolutely not comparing the severities of my issue and chronic pain as they are incomparable, however I did notice many commonalities in the pain process.

As for self-management in regards to medical issues, I have some personal experience. Since I was 16, I have been experiencing occasional seizures. After years of denial, embarrassment, and fear, I sought out medical attention. After many tests and a specialist, I was told that there was nothing physically wrong with me. I began feeling like maybe I was crazy and that they were all in my head even though I, unfortunately, had eye witnesses. Whenever I have a seizure, I keep them to myself because either people do not care, or they care too much and treat me like I am broken. That is the moment I realized I was alone and that I had to manage them in relative secrecy, by myself. Over the years I have discovered some personal warning signs and some factors that I suspect are related to the severity of my seizures. It is a part of my life, but I make choices to try and make sure that it does not take over. Additionally, I have a sibling whose life has been impacted by chronic pain, however, her story, like my informants is hers to tell.

Chapter 2: Review of the Literature

Self-Management of Chronic Conditions

As the world appears to have been built with a young and strong person in mind, much of the built environment is not suited for persons with chronic pain (Wendell, 1996). As one ages or begins to adapt their identity to that of someone living with a chronic illness, they will begin to notice themselves as the 'other'. Any limitation that would not be expected for a strong and young person is considered abnormal by society and reinforces the already established social isolation felt by persons with chronic illness (Wendell, 1996). Being a part of this marginalized group may affect one's social rights as well as their overall self-esteem (Wendell, 1996). The 'other' are strongly encouraged by society to overcome their illnesses and regain the ranks of the 'normal' (Wendell, 1996). Wendell describes that the failure to control the body and overcome one's illness is the most powerful symbolic meaning of disability (1996). Thus, the need to self-manage one's condition has become crucial to one's place in society.

A qualitative study researching self-management amongst persons with knee osteoarthritis separated participants based on their reported claim that they either did or did not participate in self-management (Morden et al., 2011). During in depth interviews, it was determined that everyone participated in some form of self-management behaviours of their condition, whether they previously claimed to or not. Participants explained that these self-management behaviours were approaches that arose out of necessity. They had become such a normal part of participants' lives, that they did not think those behaviours were relevant or worth mentioning (Morden et al., 2011). Some described taking up perceived 'healthy' activities such as exercise or alterations to one's diet in order to control their fears about future negative consequences. Yoga and other mindful interventions have been used for self-management as a

manner of decreasing pain (Bushnell, Ceko, & Low, 2013; McCracken, Gauntlett-Gilbert, & Vowles, 2007). These therapies have protective effects on the grey matter in the brain and minimize the experience of pain by connecting with pain modulatory circuits. Growing evidence shows that these interventions work on both chronic and acute pain (Bushnell et al., 2013).

Self-management techniques were described by patients as essential to maintaining a sense of normalcy in their lives, and to maintain their previously established identities (Morden et al., 2011). Self-management was described as a constant re-evaluation of strategies to keep up with their chronic conditions (Ong, Jinks, & Morden, 2011). People adapted and learned what worked for them over time, through personal experience, and the narratives of friends and families around them. Many also described that through personal experience they discovered some psychological techniques for managing their pain. For example, participants reported mentally distracting themselves so that they could continue to participate in the activities they enjoyed (Ong et al., 2011). Bushnell and colleagues (2013) conducted a review regarding chronic pain and the diverse ways that cognitive and emotional control can affect the pain experience. This review demonstrated that by mentally occupying oneself, individuals can affect their level of pain and lessen how they perceive said pain (Bushnell et al., 2013).

When an individual has an unexpected illness trajectory, such as most chronic pain patients, self-management is crucial (Åsbring & Närvänen, 2004). In a qualitative study of 25 women with unexpected illness trajectories, many turned to knowledge as a way of understanding and gaining the perception of the upper hand on their illness as well as to reduce their anxiety. These women sought out as much knowledge as possible in relation to their symptoms, until they were able to actively participate in the diagnosis process with their physicians and any decisions regarding their method of care and treatment (Åsbring & Närvänen,

2004; Larun & Malterud, 2007). Researchers have demonstrated the negative experiences and consequences of being a patient with unexplainable symptoms within the health care system and within patients' social circles (Larun & Malterud, 2007; Snelgrove & Liossi, 2013). In an effort to mitigate these negative experiences of being discredited, disbelieved and dismissed, many who suffer chose to cope with their illness by concealing it and suffering alone in silence (Aamlund, Werner, & Malterud, 2013; Larun & Malterud, 2007).

However, concealing a chronic illness is taxing and can result in being alienated and alone. Gallant and colleagues (2007) found that persons living with chronic illness received more negative judgements from their family than from friends and coworkers. Some chronic illness patients were able to talk to work colleagues more easily than family members about their illness as a form of release (Gallant et al., 2007; Vassilev et al., 2011). By telling the story of one's suffering, the storyteller reconstructs and re-processes their past in order to understand and make sense of their present and future (Charmaz, 1999). This is an important step in narrative reconstruction and managing one's condition (Charmaz, 1995, 1999). However, by telling their suffering story, they risk moral judgements from others such as not being believed. Being able to tell one's story in their own way to an audience that is prepared to truly hear and listen, is extremely important to coming to terms with an individual's illness (Charmaz, 1999). With new perspectives and changes to the self, the story can grow and change to embody the person's current and theoretical future views (Charmaz, 1999). Wendell details that by reading about how others reacted to and faced similar experiences to her own, she was able to identify, accept and overall aid her process of coming to terms with her own condition (Wendell, 1996).

Self-care interventions occasionally provided individuals with a self-care toolkit. For example, a toolkit was found to be useful and effective when implemented for depression in

populations living with chronic pain (McCusker et al., 2016). Supported or guided self-care interventions in which a trained coach monitored, supported and aided the individuals with the toolkit, were found to be more effective at reducing depression than unguided or 'pure' self-care interventions where the patient worked alone (McCusker et al., 2016). Yet the added benefits of the guided intervention did not last until the six-month follow up, resulting in an overall increase to baseline depression levels for those with chronic pain post intervention.

Self-management can be broken down into three main processes according to Schulman and colleagues: focusing on illness needs, activating resources, and living with a chronic illness (Schulman-Green et al., 2012). Focusing on illness needs, represents tasks and skills that are necessary for the physical concerns associated with the chronic illness. For example, for someone with diabetes, these tasks could encompass learning how to accurately prick one's finger and measure their blood glucose levels. Activating resources, calls upon one's community to assist in taking care of various aspects associated with the illness, including medical, psychosocial, financial and spiritual. Living with a chronic illness is a form of self-management that deals with personal growth, narrative reconstruction, and integrating the illness into one's identity. This is achieved by adjusting one's daily lifestyle to accommodate their chronic pain, finding meaning in their new lifestyle and processing one's emotions from the pain experience (Schulman-Green et al., 2012).

The Chronic Disease Self Management Program (CDSMP), is a community based self-management education program meant to improve self efficacy and chronic condition management skills (Brady et al., 2013). A meta-analysis reported that after six months of workshops, participants reported decreased activity limitations and, depressive symptoms, and improved communication skills with their physicians (Brady et al., 2013). Not only does this

improved communication not cause the negative consequences of frustration, anger, shame, negativity towards others and themselves as seen by Larun and Malterud (2007), Osborn and Smith (1998), and Snelgrove and Lioffi (2013), it improved participants' self efficacy and behavioural outcomes (Brady et al., 2013). Patients improved their self-assessments of health, energy, quality of life, fatigue, sleep problems, demonstrated improvements in pain, shortness of breath and overall decreased emergent and non-emergent hospitalization (Brady et al., 2013; Ory et al., 2013). A community based CDSMP that partnered with primary care providers to teach them to be self-management advocates, found that after these workshops they were able to aid participants to increase their use of community health care resources, such as dieticians (Liddy, Johnston, Nash, Irving, & Davidson, 2016).

CDSMP programs continued to demonstrate improved communication and relationships with physicians, as well as to reduced participants' sense of isolation, enhanced coping mechanisms and improved self-management skills, such as how to take one's own blood pressure (Liddy et al., 2016). Some benefits resulting from these programs however, do not withstand the tests of time. For example, energy and fatigue levels that demonstrated an increase shortly after the intervention, were no longer present at a long term follow up (Brady et al., 2013). Similar results were found in a Cochrane review of self-management for patients with chronic obstructive pulmonary disorder (Zwerink et al., 2014). Self-management interventions for this population improved health-related quality of life. They caused a reduction in shortness of breath, laboured breathing, and also lead to a lower probability of not only respiratory-related hospitalizations, but all cause hospitalizations as well (Zwerink et al., 2014). As the content of the self-management, and methods of delivery were extremely diverse, this review was unable to make any recommendations for self-management of chronic conditions. These programs were

also function-based and acted as a way for patients to not require medical attention from a professional, for example, by teaching how to take one's own blood pressure, resulting in less patients wasting the time of 'busy' physicians. These programs also did not offer strategies for adapting to the complex and ever-changing nature of chronic conditions and how to manage everyday life. While in many cases, self-management can be useful to improve the condition of a patient in pain, self-management itself is not a thoroughly understood concept. As self-management is slightly different from one condition to another, this thesis focused on self-management through the lens of chronic pain.

Chronic Illness and Pain

Cost of Pain

Chronic pain is a multifactorial, complex, and difficult problem to live with and to treat (Campbell & Guy, 2007; Webster et al., 2017). Chronic pain not only affects the individual experiencing it and those around them, it also affects society as a whole through health care costs. In 1998, chronic pain in Canada alone had a cost of approximately \$12 billion (Milosavljevic et al., 2015). This financial burden on society grew to \$15 billion by 2002, and continues to rise today with an estimated annual cost of more than \$55 billion in 2017 (Perry, Vandenberg, Wilson, & Tripp, 2017; Turk, 2002). Unfortunately, the cost to society does not end there, chronic pain further affects society indirectly through absenteeism from work due to extreme pain (Gaskin & Richard, 2012). A Canadian study in 2010, established that the cost due to absenteeism per year, solely due to back pain, was \$621 million (Zhang, McLeod, &

Koehoorn, 2016). Even though the overall financial cost of chronic pain impacts our society, this impact extends even further.

While pain is an individualized experience that affects everyone differently, it is a global public health concern associated with depression, unemployment, opioid use and anxiety (Cheatle, 2011). Chronic pain can cause sleep disturbances and insomnia that affect the productivity, functioning and overall quality of life of a patient (Harman, Keating, Mayes, Walsh, & MacCallum, 2014). The most common treatment for chronic pain currently is opioids, which has also begun an epidemic (Webster et al., 2017). There is an increase in the number of opioids being prescribed in Canada per year, and it is on the rise (Webster et al., 2017). Physicians have reported their concerns as to their training for providing opioid prescriptions to treat chronic pain (Webster et al., 2017). Many felt undertrained to handle such a situation, while others described falling into Fields' "doctor's dilemma". In this dilemma, on the one hand, it would be immoral for a physician to deny a patient in pain the proper treatment, but on the other hand, offering the proper treatment opens the patient up to significant risks (Fields, 2011). Medical students have reported feeling uncertain when prescribing pain medications, which may result in a misjudgement of patients' needs. While some patients may be 'drug-seekers', others may be pain patients who may not receive the prescription they rightfully deserve due to the physician's uncertainty (Webster et al., 2017). This uncertainty also impacts the dosing of medications, causing an increase in high dose prescription from 2003-2014, which has increased the rates of opioid related emergency department visits by 55% in Canada (Spooner et al., 2016).

Social Effects of Pain

Chronic illness impacts our society, with more than 50% of older Americans having two or more diagnosed chronic conditions, including heart disease, stroke, diabetes, cancer, and arthritis (Ory et al., 2013). Referring solely to chronic pain in Canada, in 2011, it was determined that 18.9 - 29%, or approximately 6 million adults over the age of 18 experienced chronic pain (Carleton et al., 2017; Gilmour, 2015; Moulin, Clark, Speechley, & Morley-Forster, 2002; Schopflocher, Taenzer, & Jovey, 2011). Half of those reported suffering this pain for over 10 years, and a third reported their pain to be severe. This prevalence increased with age and was seen to be greater in women than men (Schopflocher et al., 2011). A 12-year Canadian epidemiological study also found comparable results showing that women had a higher prevalence of chronic pain than men, but not incidence. Incidence refers to new cases of chronic pain (Reitsma, Tranmer, Buchanan, & VanDenKerkhof, 2012). This suggests that women will have a longer duration of illness compared to men, potentially due to the typically longer lifespans of women. While there were no sociodemographic risk factors found for men relating to chronic pain, women were found to have a number of risk factors, including being older, having a lower level of education, as well as being divorced, becoming a widow, etc. which were all found to increase the risk of chronic pain (Reitsma et al., 2012).

In 2015, one in five Canadian adults experienced chronic pain, and it was often unrecognized and untreated (Wilson, Lavis, & Ellen, 2015). Chronic pain is not solely an intrapersonal problem, as patients with chronic pain report high levels of self perceived burden on their significant others (Kowal et al., 2012). This self perceived burden further affects the patient, as they hold a high degree of concern for their significant other, adding additional stress to their pain (Kowal et al., 2012). Patients with chronic pain also have a much higher rate of

depression and anxiety that often goes undiagnosed and therefore untreated (Shamji, Rodriguez, Shcharinsky, & Paul, 2016). Feelings of being miserable, hopeless and suffering from insomnia ranked highly as risk factors for suicide attempts and ideation of suicide for people with chronic pain (Ratcliffe, Enns, Belik, & Sareen, 2008). Addiction is also a vital concern when caring for this population, as deaths from prescription opioids are on the rise (Webster et al., 2017).

Personal Effects of Pain

Along with negative societal and social effects, chronic pain is not without influence on the personal level as well. Living with chronic pain is akin to being a victim of torture in numerous ways (Scarry, 1985). An experience shared by both is the unpredictable nature of pain. It comes in at random intervals of time, with the sufferer never knowing when it is coming or for how long it will last (Scarry, 1985). The intensity of pain is such that all other things are masked by it, so that nothing other than the pain exists. This pain is also accompanied by a deconstruction of language, in which sophisticated speech is reduced to nothing more than guttural moans and screams at its worst moments. At all other times, the subject matter of the person's speech is monopolized by their pain (Scarry, 1985). With prolonged exposure to either chronic pain or torture, there is a destruction of a person's sense of self, their senses, and their world (Scarry, 1985).

There is also evidence that prolonged pain is detrimental to the brain, decreasing an individual's abilities to naturally control this pain within their bodies (Bushnell et al., 2013). Patients with chronic pain may develop alterations in areas of the brain responsible for cognitive and emotional modulation of pain. This can lead to a decrease in the analgesic effects of opioids

(Bushnell et al., 2013). Physician prescribed opioids are meant to function as a pain medication to provide some respite for patients suffering from chronic pain. While opioids do work in many cases, they are not without their side effects. Not only are opioids addictive and therefore dangerous, opioids have also been known to cause constipation (Coyne et al., 2015). Chronic pain patients being treated with opioids in a study conducted by Coyne and colleagues (2015), reported adding laxatives to their medications, changing the brand and type of pain medication, lessening their own doses, and/or stopping their medication altogether, in order to receive some relief from the side effects (Coyne et al., 2015). Providing that the individual with chronic pain seeks out healthcare, is capable of convincing the physician that their pain is real, and the physician reacts positively to the patient in order to prescribe opioids, the patient is then considered lucky (Campbell & Guy, 2007; Snelgrove & Liossi, 2013; Wilson, Lavis, & Ellen, 2015). However, at this point the patient has begun adapting to their opioids and requesting stronger doses to manage their pain, they have become addicted to their medications, and are also suffering the negative consequences associated with opioids, such as constipation (Coyne et al., 2015; Webster et al., 2017). It is therefore unsurprising that patients hold negative emotions towards formal healthcare.

Patients Perspectives on Formal Caregiving

Studies taken from the patients' perspective have found that many patients feel anger, annoyance and frustration towards the medical system (Campbell & Guy, 2007; Crowe et al., 2010; Larun & Malterud, 2007; Morden et al., 2011, 2014; Ong et al., 2011; Osborn & Smith, 1998; Snelgrove & Liossi, 2013). However, when patients receive collaborative care which is focused on patient empowerment and includes the patient as an active member in their own care,

patients' felt self-efficacy towards their conditions and are left with the knowledge of how to positively manage and cope with their symptoms (Bodenheimer, Lorig, Holman, & Grumbach, 2002). Although less common, this kind of care and education can result in positive health care experiences for the patients and a good trusting relationship with their health care providers that promoted understanding and increased their likelihood for referrals and proper pain treatment (Bodenheimer et al., 2002; Snelgrove & Lioffi, 2013). Regrettably, the patient - physician relationship in cases of chronic pain rarely occurs this positively.

Unfortunately, in many cases of chronic pain, biomedical markers are difficult to find or are not present, such as in cases of fibromyalgia. Rather than a health care professional declaring that they failed to find a diagnosis or that they cannot discover the origin of the patient's pain at a given time, the patient is given a psychological diagnosis. This psychological diagnosis is by default, rather than due to the presence of a psychological disorder (Wendell, 1996). It is not surprising that with these experiences, patients feel negatively towards formal healthcare. These mindsets stem from their feelings of being misunderstood, having to confront their doctors to justify themselves when biomedical markers were absent, and having to legitimize their experiences (Campbell & Guy, 2007; Snelgrove & Lioffi, 2013). They leave their physician's offices with unacknowledged concerns, often being told that their issues are psychosomatic, 'all in their head' and not the physician's concern (Larun & Malterud, 2007; Wendell, 1996). Alternatively, in cases when biomedical markers are present, and a physical diagnosis is issued to a patient, the psychological aspect remains looming over the patient's head (Wendell, 1996). Psychology is employed whenever a patient is not improving by the physician claiming that the patient simply "does not want to get well". In these cases, physicians explain that it is not medicine's fault, but rather the fault of the patient (Wendell, 1996).

The disconnect between patient and physician may be the result of poor communication (Scarry, 1985; Wendell, 1996). Patients report that they are treated as a corpse, or a body, not a person (Wendell, 1996; Wilson, Chaloner, Osborn, & Gauntlett-Gilbert, 2017). In many cases, the physician rarely listens to the patient, choosing to focus solely on the symptoms readily available. As pain is not visible, it does not receive as much attention as other issues, such as broken limbs (Scarry, 1985). In the case that the physician chooses to talk to the patient, conversations are practitioner-focused and consist of yes/no type questions (Wendell, 1996). This form of one-way conversation on behalf of the physician may be due to the physician's prior knowledge of pain cases or simply to save the physician's time. As Scarry explains in her book 'The Body in Pain', describing one's pain is a daunting task (Scarry, 1985). The person experiencing the pain must sit across from a physician that is not in pain, and somehow convince the physician that their pain is real even though it is invisible (Scarry, 1985). It is then the physician's duty to confirm or deny the severity and existence of the patient's pain while not being able to see it or touch it (Scarry, 1985). Were it that all patients had excellent persuasive skills, there would be no problem, however this is not the case. The words in which to describe chronic pain were few and poorly understood before the creation of the McGill Pain Questionnaire, which, when used properly, can aid in the categorization of pain. Therefore, patients opt to provide metaphors and analogies to express their sensations of pain to the physician (Scarry, 1985; Wendell, 1996). While some of these metaphors encompass the sensations of pain perfectly, the description they provide may be detrimental to their goal of receiving care (Wendell, 1996). For example, a woman had a large stomach ulcer and described her pain as a "crab inside her, tearing at her with its claws, eating her" (p.134). Rather than

receiving care, she was sent to a mental hospital (Wendell, 1996). The difficulties of describing one's pain and not being believed leads patients to seek relief from their pain elsewhere.

Campbell & Guy (2007) conducted a focus group for adults living with chronic pain to express their experiences and emotions throughout their entire 'pain journey'. A thematic analysis of these patients' narratives yielded rich results. When living with chronic pain, many patients felt they had unmet expectations from the health care system, and claimed they had sought out alternative therapies due to their negative feelings towards their health care practitioners (Campbell & Guy, 2007). Patients felt that they were not being helped or heard by their practitioners, which ignited their feelings of frustration and anger. Many patients in the focus group assigned the blame of their continued pain to their general practitioners, while alternative therapies such as physiotherapists and osteopaths were viewed optimistically, even though the positive effects of their treatments were short lived (Campbell & Guy, 2007).

A recurrent frustration from patients located within the literature is that patients constantly felt the need to justify their pain, and convince their doctors, families, friends and the world that it was real, and not simply psychogenic (Asbring, 2001; Campbell & Guy, 2007; Larun & Malterud, 2007; Osborn & Smith, 1998; Snelgrove & Liossi, 2013). A psychogenic disorder is a condition in which the origin or cause for one's physical symptoms arise in the mind, rather than a physical origin (Oxford Dictionary). A meta-synthesis of qualitative research around living with chronic pain led to the generation of three main themes, one of which was how chronic pain impacted their relationships when pain was perceived as psychogenic (Snelgrove & Liossi, 2013). This was discussed regarding both their relationships with family and friends, as well as their relationships with their health care providers (Snelgrove & Liossi, 2013). Several people expressed the feeling of their pain not being believed by practitioners. This

accompanied feelings of distress, frustration, anger, guilt, as well as being viewed as lazy, culpable, and many more emotions described in Table 1. They are also accused of imagining their symptoms and trying to plead for unneeded medications (Larun & Malterud, 2007; Osborn & Smith, 1998; Snelgrove & Liossi, 2013). Snelgrove & Liossi (2013) explained that this constant effort to validate the symptoms of pain that is diagnosed as psychogenic can lead to negative consequences, such as marginalization, confusion, fear, social isolation, non-adherence to medical regimens and unsuccessful rehabilitation (Snelgrove & Liossi, 2013). Patients reported adopting overly disabled behaviours to counteract these effects in an effort to legitimize their pain in the eyes of their practitioners, rather than being labelled psychogenic (Snelgrove & Liossi, 2013; Wendell, 1996). All of this resulted in the belief that they were alone, and that they no longer had faith in their health care system in regards to receiving help (Larun & Malterud, 2007; Osborn & Smith, 1998; Snelgrove & Liossi, 2013). Scarry (1985) describes this struggle using the metaphor of war. Patients are willing to ‘die for their cause’, for a diagnosis and treatment, so that at the end of the battle they can stand victorious knowing that all of their pain and struggles were worth it. A diagnosis means that they were not ‘crazy’ or ‘seeking attention’, but actually living with a medical condition (Scarry, 1985). Alternatively, if a physician does not believe or cannot prove the biomechanical or physiological origin for pain and negates using the psychological diagnosis, many patients are left to live with their pain without any diagnosis whatsoever (Aamland et al., 2013; Campbell & Guy, 2007; Larun & Malterud, 2007; Snelgrove & Liossi, 2013). Wendell (1996) describes that in these cases the individual has to choose between doubting themselves or their trusted health experts. Either the person is wrong about their own pain and it truly isn’t there, in which case they give themselves a psychological diagnosis, or they must doubt the expert opinions of their physicians (Wendell, 1996).

Table 1: Words commonly used to describe the emotions and well-being of the chronic pain experience as represented in the papers cited within thesis

Frustration	Exclusion	Dismissed
Anger	Alienation	Guilty
Despair	Rejection	Misunderstood
Bereaved	Powerlessness	Lazy
Distressed	Self-loathing	Alone
Misery	Negativity Towards Others	Burden
Isolated	Negativity towards themselves	Disconnect
Abandoned	Shame	Fight
Disgust	Helplessness	Marginalized
Pity	Decreased self-esteem	Solitary
Trapped	Social isolation	Grieving
Loss	Misjudged	Longing
Confusion	Insulted	Surrender

Help seeking is a multifactorial and complex process. Many opt not to seek medical attention for their pain for a myriad of reasons including individual, cultural and organizational elements (Bedson, Mottram, Thomas, & Peat, 2007; Morden et al., 2011; Ong et al., 2011). Morden and associates (2014) conducted a qualitative study in order to understand help seeking behaviours for persons with chronic joint pain. The decision of whether or not to consult was impacted greatly by any disruption or change in the symptoms or pain that participants experienced. If the pain suddenly intensified or became unbearable within their current coping strategies, then the likelihood for consultation behaviour increased (Bedson et al., 2007; Morden et al., 2014). The perceptions of participants in relation to general practitioners also affected consultation behaviours. The opinions of participants were that practitioners did not have much to offer patients regarding their pain other than medications (Morden et al., 2014). This outcome was undesirable to the patients as they felt they could obtain the medication by themselves elsewhere, such as over the counter or ‘street drugs’. This would achieve a similar result, without the negative psychological consequences that arise from trying to explain, defend and justify

their pain to their practitioner (Larun & Malterud, 2007; Morden et al., 2014; Snelgrove & Lioffi, 2013). Furthermore, the medication itself was not a desirable option due to its negative side effects, cost and harmful interactions with their other medications (Coyne et al., 2015; Morden et al., 2014). Medical practitioners are perceived by patients as ‘busy experts’ who should not be bothered for issues such as pain (Morden et al., 2014). These impressions are then reinforced by the extended wait times, difficulties in scheduling appointments and cost in some countries. Rationalizing whether to consult or not is a complicated decision, especially when the outcome of a clinical visit about pain is simply to leave frustrated and with a prescription for pain medication (Morden et al., 2014). For those that did choose to consult, some were referred to a specialist for further testing. This act of being given a referral from a physician acted as temporary reassurance that their pain must be real, however, it often did not yield any results and acted as a dismissive device (Morden et al., 2014). Many reported being told that their pain was age related or ‘wear and tear’ and that there was nothing that could be done except the offer of medication. Therefore the patients that chose to consult concluded that consulting was futile and reinforced the existing perceptions of general practitioners (Morden et al., 2014). Many lost all faith and trust in their practitioners as experts, and once again referred to them as having no time to devote to issues such as pain. These patients emphasized that their experiences acted as a deterrent for any further help seeking and that any relief they hoped to achieve, they would have to find themselves (Morden et al., 2014).

These avoidant behaviours of help seeking cause even further psychological damage, as the patient must continue to live without a diagnosis, without an acceptable way to relieve their pain and must legitimize their pain to everyone around them. As Campbell and Guy (2007) demonstrated, many patients are willing to try alternative therapies and view them positively,

including physiotherapy, to find some relief. Coyne (2015) stated that half of the patients involved in her study reported using at least one form of behavioural therapy to help them cope with their pain. Wilson and colleagues (2017) combined physiotherapy sessions with acceptance and commitment therapy (ACT) as a psychological framework. ACT is a behavioural therapy that focuses on developing the abilities needed in order to accept unpleasant emotions, and to help patients live with chronic conditions by targeting their problematic thinking (Wilson, Chaloner, Osborn, & Gauntlett-Gilbert, 2017). The physiotherapy exercises all had a focus on deliberate self-awareness, as well as paying attention to the cognitive, emotional and motivational aspects of movement and behaviour change (Wilson et al., 2017). Patients reported feeling heard and that their 'whole person' was taken into account with this form of therapy; as opposed to the normal frustration experienced in other therapies when psychological therapies are not included (Campbell & Guy, 2007; Morden et al., 2014; Snelgrove & Liossi, 2013). When participants described physiotherapy that was not psychologically informed, they expressed feeling disembodied sensations, hopelessness, feelings of being dismissed, unsupported and frustrated (Wilson et al., 2017). Using psychology informed physiotherapy (PIP) eliminated the feeling that patients were just a 'body' to be treated, but rather treated the 'person' by discussing thoughts and feelings. These sessions offered a safe and open environment with a multifaceted approach to health and treatment that was welcomed. The professionals were viewed less as experts, and more as a supportive party that was invested in the patients' treatments and progress (Wilson et al., 2017). Patients were encouraged to experiment without judgement, which prompted increased self-awareness surrounding their personal limitations. This overall environment even allowed participants to express their concerns with professionals, and

improved these relationships (Wilson et al., 2017). Unfortunately, this is a rare form of therapy and not readily available to many people experiencing chronic pain.

Patients Perspectives on Informal Caregiving

As formal caregiving from physicians and other professionals is less than ideal for the average person experiencing chronic pain, many patients turn to informal sources of care. Scarry (1985) describes that when one is enduring chronic pain, being able to reach out to others and receive some validation of their symptoms can mean the world to them. If no one acknowledges their pain, it is as though the sufferer is being hurt again (Scarry, 1985). Relationships with families and friends were crucial for offering much needed emotional and physical support for persons with chronic pain, which decreased their depression and increased their mood (Snelgrove & Liossi, 2013). However, for the patient, maintaining their current familial and community roles proved difficult while living with chronic pain (Larun & Malterud, 2007; Osborn & Smith, 1998; Snelgrove et al., 2013; Snelgrove & Liossi, 2013). As the inability to perform daily tasks accumulates, social and familial roles begin to deteriorate, and the members of the support system are forced to adopt new roles as caregivers and spend more time addressing health needs (Snelgrove et al., 2013). This brought about feelings of shame and guilt, as the patients perceive themselves of adding burdens on their support systems (Kowal et al., 2012; Snelgrove & Liossi, 2013; Woolf & Pfleger, 2003).

In a study on self-perceived burden, persons with longstanding pain reported elevated levels of self-perceived caregiver burden (Kowal et al., 2012). In the study by Kowal et al. (2012), 73% of chronic pain participants reported high levels of caregiver burden which is

comparable to the perceived caregiver burden seen in stroke survivors, and is higher than the burden reported by cancer patients. This burden and guilt of holding back the members of their support system from living their own respective lives put added strain on these relationships. Over time, the sympathy and support of family and friends fades, especially if the person did not have a diagnosis or medical explanation to legitimize their pain (Aamland et al., 2013; Campbell & Guy, 2007; Larun & Malterud, 2007; Snelgrove & Lioffi, 2013; Wendell, 1996). Wendell (1996) describes that this burden may stem from an adult's need to be independent as imposed by society, especially within the acts of daily living. She also describes an alternate source for this sense of burden as is imposed by physicians; the psychological attitude of a patient. The psychological thoughts that a patient's health is not improving may be due to the patient themselves not wanting to improve. Providing that the family or other members of the patient's support system believe this to be the case, the family members are more likely to consider the help that they are providing the patient to be a burden (Kowal et al., 2012; Wendell, 1996). With these strained relationships and negative emotions encompassing the person with chronic pain, their sense of self and identity enters a vulnerable state.

Self and Identity

The theme of self, recurred often within the literature. Participants in numerous studies reported a loss of identity due to their pain and loss of functioning (Campbell & Guy, 2007; Charmaz, 1999; Crowe et al., 2010; Osborn & Smith, 1998; Snelgrove & Lioffi, 2013). Osborn and Smith (1998) conducted semi-structured interviews with women that live with chronic pain in order to understand their experiences. These women reported making constant efforts to understand their pain. Even though much of their time was spent in and out of health care

facilities, these women reported that they felt uninformed and did not truly understand their condition or why they could not control it (Osborn & Smith, 1998). This lack of understanding and control of their pain caused participants to express their pain and their bodies as separate entities to themselves (Crowe et al., 2010; Osborn & Smith, 1998). When discussing their pain, many women compared themselves to their past, referencing a person different from who they are now. Their old self was described as their ideal self, a person without pain. This idealized 'person' revealed the participants' sense of what they had lost and the change that pain had brought to their lives (Osborn & Smith, 1998). Crowe and her colleagues (2010) conducted similar semi-structured interviews with both men and women living with chronic back pain. Their thematic analysis yielded comparable results to those of Osborn and Smith, indicating that sex is not a relevant factor in this case (1998).

A main theme found in a number of qualitative studies was the unpredictability of the pain (Crowe et al., 2010; Morden et al., 2014; Osborn & Smith, 1998; Snelgrove & Liossi, 2013; Wendell, 1996). Participants discussed how they were frustrated and did not understand the erratic nature of their pain. Many also expressed having to be attentive to the needs of their bodies to minimize the potential for pain. In numerous cases this led to a need for vigilance, and participants had to become very cognisant of their bodies (Crowe et al., 2010). The manner in which daily tasks, social interactions and everyday movements were performed had to be altered to accommodate their bodies and their pain. Participants expressed that this added restrictions to their lives and additional fears of not being able to do the things they love or enjoy because it may cause them pain (Crowe et al., 2010).

There was also the theme of a disconnect between their bodies and themselves. The self-objectification of their bodies inspired the thinking that their lack of functioning was the fault of

their bodies, not them; that their bodies had betrayed them (Crowe et al., 2010; Scarry, 1985). Wendell (1996) explains that everyone is subjected to cultural pressure to deny their bodily weaknesses, to feel ashamed of their differences and to objectify any part of themselves that falls outside the category of the 'normal'. In order to live with chronic pain, participants often referred to listening to what their bodies had to tell them and then complying to their bodies' wishes, all while sacrificing their own desires (Crowe et al., 2010). These sacrifices to their pain over time altered the participants' lifestyles and eventually their senses of self. Their pain caused participants to give up careers, social obligations and activities that they previously enjoyed (Crowe et al., 2010; Larun & Malterud, 2007; Osborn & Smith, 1998). Over time, these accommodations to their pain had a lasting effect on how participants perceived themselves. Their personalities changed, their self-esteem lowered and there was a constant expression by participants of not perceiving themselves the way that they used to be or wanted to be (Crowe et al., 2010).

Feelings of loss occur at many levels, including physical loss, emotional functioning, psychological loss, and personality loss. The physical loss of functioning occurs wherein participants have expressed having to avoid certain movements in order to avoid pain (Crowe et al., 2010). Avoiding such movements can have a drastic impact on one's self esteem, physical health, and on one's career, by ceasing those movements, patients may be forced into financial instability (Crowe et al., 2010; Larun & Malterud, 2007). There is a loss in emotional functioning, wherein relationships become damaged and the overall experience of chronic pain leads to the negative emotions of frustration, anger and despair (Crowe et al., 2010; Larun & Malterud, 2007; Osborn & Smith, 1998; Snelgrove & Liossi, 2013). There is also psychological loss of functioning, wherein their pain has caused them to alter their lifestyles, and they are not

able to fulfill their previous social or familial roles (Osborn & Smith, 1998). In many cases symptoms of pain were said to have a large impact on their social lives, including at work or school (Larun & Malterud, 2007; Wendell, 1996). Personality was also described as being affected by their pain. This came from their altered self-image due to their pain and overall change in daily regimens (Crowe et al., 2010). Campbell and Guy (2007) described participants' pain as something to fight, overcome and persevere through. Wendell (1996) explains this nature to have to 'overcome' one's own disability to appease society and appear as though the individual is not 'giving up' on recovery or improvement.

The consequences of chronic illness affect the individuals' sense of self and their previously established identities (Asbring, 2001; Larun & Malterud, 2007). Through physical, emotional, and social costs associated with these symptoms, individuals often found themselves socially marginalized, and living a solitary, passive life as a 'new' person (Asbring, 2001; Larun & Malterud, 2007). Larun & Malterud (2007) researched people living with chronic fatigue syndrome, which shares many of the same symptoms as chronic pain. They discovered key themes which emerged from the data, such as, patients reported feeling controlled and betrayed by their bodies and felt a change in identity due to their illness (Larun & Malterud, 2007). Many reported associating feelings of exclusion, alienation and powerlessness with the parts of their bodies that felt pain and were difficult to control (Osborn & Smith, 2006). Osborn and Smith (2006) discuss how participants' self-concept was affected due to their chronic pain. It is described as dualism, in which the specific body parts that are dysfunctional or painful are described as separate from the person themselves. Participants admitted that prior to their pain, they rarely gave any thought to their bodies, short of cosmetic, but after their pain began, their bodies became the sole purpose for their fractured identities (Osborn & Smith, 2006).

Morden and colleagues (2011) found comparable results of a struggle in identity. Chronic conditions often cause biographical disruption, which can cause individuals to undergo narrative reconstruction in order to recreate themselves in a new image (Morden et al., 2011). This involves sacrificing a previously established identity and by potentially adding assorted aids, such as mobility devices, in order to maintain certain activities and former social and familial roles (Morden et al., 2011). The biographical disruption occurs gradually (Asbring, 2001). It begins by feeling that something is wrong with your body. Subsequently, there are feelings of longing for your past capabilities and grieving your past body. This all results in objectifying your painful, dysfunctional body as a separate entity to yourself. A complete biographical disruption is described as the new self living outside of the old self, without any integration with the earlier identity (Asbring, 2001). This is not, however, clear or definite in all illness scenarios, and in many cases biographical disruption is expressed as a complete or partial change of identity (Asbring, 2001).

A large part of one's identity lies within their work (Asbring, 2001; Larun & Malterud, 2007; Wendell, 1996). Chronic pain symptoms often make it difficult to work, or at least to maintain one's current workload due to the pace of life, which takes a toll on pre-established work and social identities (Aamland et al., 2013; Larun & Malterud, 2007; Wendell, 1996). By removing or limiting the time spent working, self-esteem plummets and both financial and social identities become at risk. Many participants explained that the benefits of maintaining their employment outweighed the risks and resulting symptoms of their illness (Larun & Malterud, 2007; Wendell, 1996). Ong and colleagues (2011) discovered that all of their participants experimented with some sort of assistive device in order to maintain their routines rather than willingly altering them; yet even with the implementation of aids, the symptoms of pain persist

throughout the actions until the painful actions cease. Despite this, many choose to fight their bodies as an attempt to hold on to their past identities, choosing to incur pain and all the associated symptoms until they no longer could (Aamland et al., 2013; Morden et al., 2011; Ong et al., 2011). This resulted in feeling alienated and like an increased burden on those in nearby proximity. This burden places strain upon relationships and is often described as the reason for separations (Campbell & Guy, 2007; Larun & Malterud, 2007; Snelgrove & Liossi, 2013). Given this strain, and the subsequent feelings of isolation and loneliness, it was described as a time to come to terms with a new identity. Acceptance of this new identity, however, came easier to some than others. Those suffering longer without a diagnosis took more time to come to terms with their new illness identity, than those that received a diagnosis earlier on (Aamland et al., 2013; Asbring, 2001).

The process of accepting one's new self began by understanding one's limits and finding new activities to enjoy that corresponded with one's capabilities (Asbring, 2001). When an enjoyed activity was no longer within the realm of possibility, participants reported replacing it with a new activity. That replacement of activities aided in the separation of their old and new identities (Asbring, 2001). Participants sometimes attempted to restore their previous identities by performing their former routines or activities. Unfortunately, many of these cases resulted in failure and disappointment. Similarly to the fashion in which persons with chronic pain compromised their pain to maintain employment, many participants opted to return to their old lifestyles and identities briefly in order to maintain crucial familial roles despite knowing that returning to these roles would cause them further pain (Asbring, 2001; Larun & Malterud, 2007; Morden et al., 2011; Ong et al., 2011).

Chronic illness is not solely negative, with many reporting positive outcomes from their illness and subsequent new-found identities (Asbring, 2001). The limited capabilities associated with chronic illnesses demand change. It is within this change that many participants were able to pause and re-evaluate their lives. They would prioritize and focus on what truly mattered to them. A new perspective was achieved by some who claimed to appreciate certain activities more, since their abilities to participate in them was altered or removed altogether (Asbring, 2001). This was generally accompanied by new values and an appreciation for simple mundane tasks that were formerly taken for granted. Many also presented having improved sleep and more time to spend with their children and grandchildren (Floderus, Göransson, Alexanderson, & Aronsson, 2005). This positive perspective due to their illness does not exist on its own. The same participants that express their joy and enlightenment since their illness, also expressed their hopelessness in the face of their very same illness within the same conversation (Asbring, 2001).

These processes of biographical disruption and narrative reconstruction due to chronic pain follow many similar stages to those of popular grief models for death (Kübler-Ross, Wessler, & Avioli, 1972). The Kübler-Ross model follows five main stages: denial, anger, bargaining, depression, acceptance (Kübler-Ross et al., 1972). While those with chronic pain are not experiencing death or dying, the experiences are paralleled in many ways. In the self-management of chronic pain literature the stage of denial is highly present. Participants often reported that they had been experiencing pain for a prolonged period of time prior to deciding to seek health care (Campbell & Guy, 2007). This stage was explained as participants not believing that their pain warranted a visit to a physician. Chronic pain patients experience denial of the severity of their pain until they can no longer bear it, at which point they choose to consult (Campbell & Guy, 2007; Snelgrove & Lioffi, 2013). The negative experiences these individuals

go through with their health care providers of anger and frustration mirror the Kübler-Ross model perfectly. Campbell and Guy (2007) capture this phase in their article entitled “Why Can’t They Do Anything for a Simple Back Problem?”. A theme in their article is in relation to participants’ unmet expectations of their health care providers. Individuals with chronic pain expected a diagnosis and, when none was provided, they became angry and frustrated. If pain medication was provided, patients felt that they were simply being sent away, and patients reacted with anger. Similar to Kübler-Ross and colleagues (1972), there was very little that physicians could do that would not result in anger (Campbell & Guy, 2007; Kübler-Ross et al., 1972). Bargaining also appears often in chronic pain research in the midst of narrative reconstruction, in which individuals understand they have chronic pain and bargain that if they implement aids, they can maintain their previous lifestyle and identities (Morden et al., 2011). Depression is typically seen in the contexts where an individual living with chronic pain has no diagnosis and, is not believed by those around them, which has caused severe strain on relationships and the individual has then chosen to suffer in silence alienated and alone (Aamland et al., 2013; Larun & Malterud, 2007; Snelgrove & Liossi, 2013). The final stage of acceptance occurs when the individual admits their chronic pain is permanent and adjusts their lifestyle and sense of self accordingly (Asbring, 2001; Charmaz, 1995). The grief model allows people to compare and assess themselves according to what is ‘normal’ for others that have undergone a similar phenomenon. As the chronic pain experience is highly individualistic, having a model or a template to compare oneself to acts as a type of self-management in which the participant is looking for their new normal while living with pain.

Although chronic illness threatens the integrity of the self, patients describe many ways of living with an illness, rather than being controlled by their illness. It is possible to ignore it,

minimize it, fight it, work around it, or embrace it (Charmaz, 1995; Morden et al., 2011; Osborn & Smith, 2006). While each of these techniques work in relation to finding a way to live with the illness, when reconstructing a new identity and sense of self with an illness, Charmaz (1995) states that it is important to adapt to the illness. By altering one's life to accommodate the losses that arise with chronic illness, individuals are able to reconnect their body to their self (Charmaz, 1995). Adapting, however, takes time. First, one must express an altered body. This is seen as objectification and a separation of one's self from their body (Asbring, 2001; Charmaz, 1995; Crowe et al., 2010; Morden et al., 2011; Osborn & Smith, 2006). The second step to adapting is assessing one's altered body (Charmaz, 1995). This is expressed as getting to know one's limits, weighing decisions, changing perspectives and making sacrifices (Asbring, 2001; Charmaz, 1995; Morden et al., 2011). Lastly, individuals should stop trying to control and fight the illness, but rather accept and surrender to it (Charmaz, 1995; Wendell, 1996). This implies that there is no winner in this fight, and that it is no longer an individual versus an illness. It is the understanding that the illness is not going away and that it is a part of the individual's identity and new sense of self (Charmaz, 1995).

Wendell describes the phenomenon of pain by using the analogy of a radio playing in the background. If she focuses on it, then she has to fight through it. Alternatively, if she accepts that it is there and 'makes friends with it', she can work with it (Wendell, 1996). Some people choose to focus on the pain for prolonged periods of time so that they are able to 'tune' into their pain and relax into it. Listening to the body, hearing the pain, and accepting it allows the mind to focus on other important bodily cues (Wendell, 1996). Similar to Charmaz, once the pain is accepted, you are able to take on new identities (Charmaz, 1995; Wendell, 1996). Wendell employs the term transcendence within her pain. It encompasses two concepts, neither of which

negate the other, but simply exist together. For example, ‘My body is in pain, but I am happy’ or “I am sick, but happy”. By acknowledging the illness, accepting it as a part of who you are, but also understanding that you can rise above it and not be defined by it, you are transcending your illness (Wendell, 1996). Being conscious of your pain, but being able to work through it aids in overall coping, self-management and attitude of living with chronic pain (Wendell, 1996).

Defining Self-Management

Wendell explains through her analysis of the term ‘disability’ that definitions are crucial to understanding individual concepts (Wendell, 1996). Self-management is a difficult concept to describe and has many conflicting definitions associated with it. Throughout the literature it is used both as a synonym for other terms such as self-help or self-care, and also as a different concept entirely (Richard & Shea, 2011a; Richards, 2004). It is crucial to highlight the confusion within these terms in the literature to determine what self-management and associated terms truly mean (Wendell, 1996).

It is common within the realm of academia for terms to have situational meanings. These terms often exist within faculties or disciplines, share the same meaning, and are well understood by the majority of researchers within that field of study (Wendell, 1996). It is then not out of the ordinary for researchers to publish an article using one of these terms without feeling the need to define it for the reader. Many good researchers fall victim to this phenomenon. For example, Cosby, Francis, & Butler (2007) wrote:

The evidence generated from primary-care research, showing that the most common respiratory infections could be safely managed without the need for immediate assessment

or antibiotic treatment, created a safe environment for policymakers and physicians to consider alternative unscheduled care arrangements. Patients requesting urgent consultations for infectious indications were, with increasing frequency, encouraged to engage in self-care. For example, delayed prescribing—when a physician gives a prescription to a patient with the instruction that they should only fill the prescription if symptoms worsen—became a common practice among primary care physicians.” (p. 2)

In this case, Dr. Cosby and his colleagues used the term self-care in a manner which they functionally understood yet did not explain what specifically the patient is meant to do for this self-care (2007). The physicians simply delayed prescribing, so that the patient should only fill their prescription when, or if their symptoms worsen. This publication also does not detail what the patient should do to care for themselves prior to the potential worsening of their symptoms, nor to what extent the patient’s symptoms need to worsen to, before filling their prescription. This is one of the many traps that researchers fall into and also demonstrates the need for a universally understood definition for terms such as self-care, self-management, and self-help.

In some cases within the literature, researchers attempt to explain self-management through a comparison with another term. Unfortunately, relating a misunderstood term with another misunderstood term, while defining neither of them, does not aid the understanding of either terms. For example, the following is an extract from Winkley and colleagues’ (2016) journal article “Low attendance at structured education for people with newly diagnosed type 2 diabetes”:

“Diabetes self-management education (DSME) for people with newly diagnosed Type 2 diabetes (T2DM) is the cornerstone of diabetes self-care.” (Winkley et al., 2016)

This example exemplifies the ambiguity of self-management and its related terms. Dictating that diabetes self-management is crucial to diabetes self-care may be a key element in distinguishing between these two terms. However, without previously understanding of what either diabetes self-management or diabetes self-care entail, this excerpt causes confusion. On the other hand, Richards (2004) states that self-help, self-care, and self-management are all terms used interchangeably to describe the same phenomenon. Adopting this understanding, the previous quote by Winkley (2016), is explaining that self-management education is the key to self-management. This is an important aspect which will aid self-management adoption in the future, nevertheless, this quote still leaves the reader mystified as to what self-management actually is and entails. In a later effort, Winkley (2016) attempts to explain self-care by addressing the barriers associated with it:

“Well known barriers to optimal diabetes self-care include psychological and social factors and low levels of health literacy may discourage attendance or prevent those affected from benefitting from this mode of self-management support.” (Winkley et al., 2016)

The study continues to examine attendance at a ‘Diabetes Education for Ongoing and Newly Diagnosed (DESMOND)’ programme. The curriculum highlights: thoughts and feelings of the participants with diabetes, how diabetes affects the body, monitoring medication and dietary control, physical activity, and planning for the future (Winkley et al., 2016). This education programme exemplifies some behaviours that appear in other articles as forms of self-management, even though there is no clear definition provided (Bal et al., 2016; Ellis, Boger, Latter, Kennedy, Jones, Foster, & Demain, 2017). Assuming that self-care is a different construct from self-management, in this excerpt self-care is only defined by the challenges of low attendance to these education programmes (Winkley et al., 2016).

Within the literature, the term self-care is misunderstood. While there is not a commonly shared definition within the literature, the World Health Organization published a definition in 1983, which provides an overarching idea of what self-care is:

“Self-care in health refers to the activities individuals, families, and communities undertake with the intention of enhancing health, preventing disease, limiting illness, and restoring health. These activities are derived from knowledge and skills from the pool of both professionals and lay experience. They are undertaken by lay people on their own behalf, either separately or in participative collaboration with professionals.” (World Health Organization, 1983)

This all-encompassing definition allows for numerous actions from varying origins and performed in different situations for differing reasons. However, in relation to the specific self-care behaviours, there is much debate. Robyn and colleagues (2011) posit that self-care behaviours are the fashion in which one medicates:

“Traditional methods of self-care involve utilization of pharmacopoeia products, such as local plant and herbal remedies that are either prepared by members of the household or purchased from local suppliers.” (Robyn et al., 2011)

Whereas, others disagree with this and state that self-care behaviours should be performed without the use of medication:

“Self-care is part of the non-pharmacological treatment, comprising key behaviours that can improve disease outcomes.” (Peters-Klimm et al., 2013)

The overall premise from the World Health Organization is met in either case (World Health Organization, 1983). In both cases these behaviours are being implemented in order to enhance

one's health and limit illness (Peters-Klimm et al., 2013; Robyn et al., 2011). This perplexing lack of clarity demonstrates a gap in the literature, in relation to understanding the true essence of self-care.

Self-help is another term used synonymously with self-care and self-management (Richards, 2004). Similarly, self-help is also a vague and ambiguous term. Wilson and Zanderberg (2012) describe self-help as an overarching form of treatment, self-administered according to a predesignated protocol:

“Self-help interventions entail the independent use of a treatment manual or protocol following step-by-step instructions contained in a book or via a web-based system. The goals are both to educate individuals about the nature of their disorder and to equip them with specific skills to overcome their problems.” (Wilson & Zandberg, 2012)

This quote provides many key attributes of self-help interventions including examples of potential health technologies an individual can use independently. The goals of self-help interventions are to educate and develop skills related to one's disorder (Wilson & Zandberg, 2012). Blankers and associates (2011) mirror this statement of self-sufficiency:

“IS (internet self-help) is a stand-alone, internet-based, non-therapist involved, fully automated, self-guided treatment program, which based on a CBT/MI treatment protocol.” (Blankers, Koeter, & Schippers, 2011)

This definition provides a clear and concise ideal for what self-help truly is. According to Blankers et al. (2011) and Wilson & Zandberg (2012) self-help is an individualized activity, with no therapist involvement whatsoever. Using self-help as a form of treatment should be considered a separate and complete treatment in and of itself (Blankers et al., 2011).

Unfortunately, not all researchers share these opinions fully. Levy and colleagues (2016) agree that self-help can exist as an intervention without the involvement of a professional, however, it is still self-help even with the inclusion of a therapist.

“Self-help interventions can be accessed either with little or no contact with a therapist (unsupported/non-guided self-help) or in parallel with individual sessions with a clinician (supported/guided self-help).” (Levy, Holtum, Dooley, & Ononaiye, 2016)

This excerpt demonstrates that self-help may not be a simple, singular construct, but rather a term that explains a form of care, on a spectrum, from unsupported to supported. Defining self-help becomes an even more muddled construct with the addition of self-help groups. Within the debate over the extent to which one is alone or supported in their self-help, groups are formed to aid these persons with their challenges (Chaveepojnkamjorn, Pichainarong, Schelp, & Mahaweerawat, 2009):

“Self help groups can be defined as an organization of willing persons with similar problems or who have the same disease, who can share experiences about their problems and discuss the solution to these problems.” (Chaveepojnkamjorn et al., 2009)

This introduction of self-help groups poses a new question, is one truly independent in their self-help if they participate in a self-help group? According to earlier definitions of self-help, the term ‘self’ seems to refer solely to the extent of interactions one has with a therapist (Blankers et al., 2011; Levy et al., 2016; Wilson & Zandberg, 2012). Adopting this mentality, providing that these groups are comprised solely of non-therapists, it may still be considered self-help. Without a clear all-encompassing definition explaining self-help, the meaning is lost.

The term self-management itself is featured heavily in the literature with regards to chronic illness and specifically chronic pain. Regrettably, this term is also poorly understood and defined:

“Self-management is defined as education and support provided by health professionals and/or lay leaders to increase patients’ ability and self-confidence in managing their health and well-being.”(Hutting et al., 2016)

This passage explains self-management as a tool provided by someone else, to help an individual manage their symptoms. In contrast, Randall & Neubeck (2016) explain that self-management is when the individual themselves, actively participate in their own care:

“Self-management can be simply defined as active participation by people in their own health care” (Randall & Neubeck, 2016)

‘Active participation’ itself is not clear and can mean a myriad of things ranging from reading about their symptoms online, to booking an appointment for surgery. Regrettably, the confusion surrounding self-management does not end here. Not only does Hutting et al. (2016) state that self-management is something provided by an external source, and Randall & Neubeck (2016) state that the onus is on the individual, Smith and colleagues (2007) state that self-management exists somewhere in the middle.

“Self-management implies a process of change from a traditional physician-dominated consultation to where responsibility is in part assumed by the patient. With the patient education movement to self-management was an expectation that patients were to take on more responsibility. The increase in responsibility presumes that all patients have the ability to problem solve their personal health issues.” (Smith, Mitchell, & Bowler, 2007)

The numerous discrepancies surrounding self-management, self-care, and self-help, reveal a gap in the literature. The current definitions are not only vague and ambiguous, but also provide blatant inconsistencies. These definitions also seem to ignore the wealth of literature on embodiment related to chronic illnesses and pain. They are deficit-oriented and intervention specific in which they craft the definitions to fit the intervention, rather than crafting the intervention to fit the definition and the problem. The definitions of self-management and related terms also ignore the complex and changing nature of illnesses such as chronic pain. These definitions often ‘offload the problem’ to the patient, indicating that any improvement in the patient’s care is the patient’s own responsibility and has nothing to do with the physician. The literature dictates that this behaviour by physicians is a source of frustration for patients, which is not considered in the definitions of these terms for chronic pain.

To understand what self-management and its associated terms truly mean, a comprehensive literature search and document analysis needs to be conducted to derive commonalities for these definitions. On top of this, to determine what these terms mean in relation to chronic pain, qualitative, rich, and deep interviews need to be conducted to truly understand the chronic pain self-management phenomenon. These methods are open and not deficit-oriented, allowing the participants to truly express what chronic pain self-management means to them, and to fully describe this complex experience.

Chapter 3: Methods

Theoretical and Philosophical Frameworks

A theoretical perspective is the philosophical lens with which a person views reality, the accumulation of knowledge, and society in general (Crotty, 1998). A researcher must be aware of their theoretical perspective, as their assumptions of reality will shape their methods and approach to research (Crotty, 1998). In this study, the researcher has employed a social constructivist interpretive framework. Creswell (2013) explains that this framework seeks to understand the subjective meanings people construct in association with the world. Through each and every experience a person has, subjective meanings are created in association with other people or objects. These meanings add up to a person's overall complex worldview, which may differ drastically to that from another person (Behnke et al., 2013; Creswell, 2013). In research, the objective is to ascertain the views of each participant as they have constructed them, around a particular experience. This will encompass any and all social, cultural and historical norms that may pertain to the given experience (Creswell, 2013; Lincoln & Denzin, 1998).

Along with a theoretical framework, a researcher must make a philosophical assumption that will best accommodate their research (Creswell, 2013). For this study, the ontological issue was the focus. This issue relates to understanding the nature of reality (Creswell, 2013). Through the social constructivist framework, the assumption has been made that everyone constructs their own realities through lived experiences and interactions with others (Behnke et al., 2013; Creswell, 2013). These realities may differ between individuals, all of whom are experiencing the same phenomenon, or they may share commonalities. It was the role of the researcher to report these different realities as accurately as possible in order to truly understand the underlying phenomenon (Creswell, 2013).

Philosophical Methodology

Phenomenology, at its most basic form, is the study of a phenomenon (Vagle, 2016). It has long since evolved into the investigation of subjective realities and truths that exist for each individual about how they view themselves and the world around them. Creswell explains that the purpose of phenomenology is to describe the common meanings associated with lived experiences of individuals surrounding a phenomenon (2013). The belief of the researcher is that the essence of the phenomenon and how it manifests and affects humans can be understood by studying these lived experiences (Moustakas, 1994; Simmons & Benson, 2013; Vagle, 2016).

Phenomenology, however, has expanded and developed over the years into two key streams: Transcendental Descriptive Phenomenology fathered by Husserl, and Hermeneutic Interpretive Phenomenology employed by Heidegger (Creswell, 2013; Moustakas, 1994; Vagle, 2016). For the purpose of this research study, Giorgi's modified Husserlian descriptive phenomenology was utilized (Giorgi, 2009). Husserl described that prior to conducting any research, one must adopt the concept of 'epoche' (Creswell, 2013; Moustakas, 1994). Epoche is derived from a Greek word, meaning to refrain from judgement, and to stay away from the ordinary fashion of perceiving things (Moustakas, 1994). Husserl claims that one should eliminate all their suppositions regarding the phenomenon of interest, which will allow for true knowledge to rise above any doubt (Behnke et al., 2013; Giorgi, 2009; Moustakas, 1994). In theory, once a researcher has achieved this manner of thinking and perceiving the world, they have adopted a transcendental phenomenological attitude (Giorgi, 2009; Moustakas, 1994). To then search for the essence of a phenomenon, the next step is transcendental phenomenological reduction (Moustakas, 1994). Transcendental, refers to moving beyond the everyday perceptions and perceiving everything freshly. Phenomenological, refers to transforming every aspect of the

world into discrete phenomena. Lastly, reduction refers to obtaining the source of meaning (Moustakas, 1994). This reduction separates out everything that is not essential to the meaning of the phenomenon, while still remaining true to the original experience. Dahlberg (2006) explains that if too much is reduced from the essence, it would begin to describe an entirely different phenomenon altogether. Using this methodological approach allowed the researcher to perceive each experience in an open and fresh manner, separately and in its totality. By adding Husserl's third step, the concept of imaginative variation, it creates a detailed, textural description to grasp the structural essences of experiences, aiming to achieve 'eidos', the pure essence and meaning of an experience (Giorgi, 2009; Moustakas, 1994).

The concept of epoche in transcendental phenomenology is to capture the essence of experiences of the participant without incorporating any of the researcher's own meanings or biases. Husserl described that a researcher should be free of prejudgements, suppositions, biases and preconceived ideas of the desired study topic in order to perceive the phenomenon with fresh eyes (Behnke et al., 2013; Creswell, 2013; Giorgi, 2009; Moustakas, 1994). In modern research, this process of completely eliminating one's suppositions is close to impossible. However, much can be done to achieve a similar result, for example, bracketing out one's own prejudice and experiences can be implemented in order to allow the views of the participants to truly shape the study (Creswell, 2013; Giorgi, 2009). To bracket oneself involves reflecting, discussing, and recording one's own experiences regarding the phenomenon. By doing this, the researcher acknowledges her own experiences and can set them aside in favour of focusing on the participants' experiences. While in an ideal scenario this method acts to eliminate the experiences of the researcher, often the researcher's biases can still be seen within the analysis of data (Creswell, 2013). Dahlberg (2006) proposes another option: not to bracket out the

researcher's experiences, but rather to bridle them. The assumption that a researcher can completely cut off their pre-conceptions and understandings of a given phenomenon is impractical, and in many cases, impossible in the lifeworld (Behnke et al., 2013; Dahlberg, 2006). Using the bridling technique allows the researcher to hold onto some predeterminations of the phenomenon, but not to judge or assume too quickly (Dahlberg, 2006). Similar to a horse, Dahlberg explains that one's understandings should be given slack. By doing so, the researcher is distanced from their pre-conceptions and therefore open to new and fresh understandings of the phenomenon from the participants (Dahlberg, 2006).

Data Collection Procedures

This section will be described in two phases: the concept analysis phase and the interview phase. The concept analysis phase consists of the process in which the definitions for each self-management related term were created. This phase was conducted and completed prior to the commencement of the interview phase. The interview phase utilized the findings of the concept analysis phase within its process which is also described further in this section.

Concept Analysis Phase

This search was not intended to reach saturation of the possible literature having to do with the desired terms, but rather to execute a search under reasonable parameters to understand the working definitions of these terms as they are being used within the literature. Research articles were identified for inclusion from eight academic databases, that publish information regarding Self-Help, Guided-Help, Self-Care, Patient-Driven Health Care, Self-Management, and Coping within the Applied Health Science field.

A preliminary search was conducted with other parameters such as, without the addition of ‘applied health science’, and by adding the term ‘health’ to the desired keywords. In all cases, the results were similar. The reasoning for the addition of ‘applied health science’ to the search criteria, was in order to obtain the most specific, and applicable, occupational definitions of the terms, within the field of applied health sciences.

The keywords were entered as follows:

- Self-Help + Applied Health Science
- Guided Self-Help + Applied Health Science
- Self-Care + Applied Health Science
- Self-Management + Applied Health Science
- Patient Driven Health Care + Applied Health Science
- Coping + Applied Health Science

In order to obtain the most relevant and recent definitions in the literature, the following databases were used: Google Scholar, James A. Gibson Library Super Search, PubMed (Ovid), Medline (Ovid), Web of Science, Cochrane EBM reviews, PsycInfo and the World Health Organization (WHO). To address the relevancy of the definitions, only the research articles found on the first five pages of the search per keyword selection, per database were included. More relevant research articles may have been located on subsequent pages, however for the purpose of this research, all articles following the first 5 pages were not included. Google Scholar provides a standard list of 10 research articles per search page, whereas other databases such as, the James A. Gibson Library Super Search provides a list of 50 articles per search page.

To remain consistent throughout this search, settings for all research databases were adjusted to yield a list of only 10 articles per search page. This resulted in 50 potential articles, per database, per keyword combination; resulting in the base of 2500 possible research articles. To ensure that the most recent research was found, the search was limited to only include articles that have been published within the last 10 years, from 2007-2017. Due to the language restrictions of the researcher, only articles written entirely in English were included. Providing a research article defined more than one of the pre-established terms, both definitions were extracted and included for analysis for their respective terms, regardless of the search origin of the article. The reference lists of the included articles were also searched for definitions and were included for analysis regardless of their date of publication.

Each and every included article was coded in a database. Were any articles to appear repeatedly, the duplicates were identified and removed. The remaining articles were screened through the inclusion/exclusion protocol. Thorough tables were created for each coded term based on the inclusion criteria. The principal student investigator used thematic analysis to break down each definition into its core meanings. This process involved memoing in the margins of the tables. These memos became codes, which were sorted, counted and then used to create core themes per term. Following this process, the core themes of each term were conglomerated into definitions, which were then converted into plain language. These definitions were used during the interview phase to gauge participant responses to how the academics define self-management and its associated terms, as well as during the data analysis phase, at which time the plain language summaries were compared to the transcribed interview data to determine the

similarities and differences between the definitions of self-management within the literature and patient perceptions of self-management.

Inclusion/Exclusion Criteria

1. Must contain a definition of one or more of: Self-Help, Guided Self-Help, Self-Care, Self-Management, Patient Driven Care, or Coping.
2. Must be within the field of Applied Health Science research.
3. Must be peer reviewed.
4. Must be published between 2007-2017.
5. Must be entirely available in English.

Interview Phase

Following the concept analysis phase resulting in the creation of both academic, operational definitions as well as plain language definitions for each self-management related term, semi-structured interviews were conducted. Participants were asked to define each of these terms as they understood them and were then, subsequently shared the plain language definitions derived from the concept analysis phase for comparison.

Sample

Purposeful sampling was used to select individuals capable of providing rich description to further the understanding of a phenomenon. Using this criterion sample ensured the depth required of phenomenological research (Creswell, 2013). Eligible participants consisted of both men and women over the age of 18 with self-identified chronic pain lasting at least three months. Participants were all residents of Ontario and had a fluent understanding of the English language. To achieve sufficient depth in phenomenological research Polkinghorne suggested interviewing between 5-25 participants in order to reach saturation (Creswell, 2013). As the purpose of phenomenology is to describe the meaning of the phenomenon for a small number of people that experienced it, Dukes described the ideal sample for phenomenological studies to be 3-10, which was further validated by Riemen, who also chose to study 10 individuals during phenomenological analysis (Creswell, 2013). Morse and colleagues, described saturation as indicating all aspects of a phenomenon to ensure validity and replicability of results (Morse, Barrett, Mayan, Olson, & Spiers, 2002). Regarding self-management of chronic pain, an estimated 10 one-on-one participant semi-structured interviews were to be conducted based off of similar studies by Osborn and Smith and Snelgrove and colleagues, as well as the recommendation of Creswell, Dukes and Rieman (Creswell, 2013; Osborn & Smith, 1998; Snelgrove et al., 2013). However, interviews were to take place only until the research achieved saturation, which occurred at seven interviews.

Participants

Saturation occurred after seven in-depth interviews which yielded sufficient data to account for the meanings participants associate with their self-management of chronic pain. Participants were comprised of seven self-identified chronic pain patients, represented by six female and one male participant. The years of participants experiencing chronic pain ranged from 2-30 years, with a mean of 10 years with chronic pain. As participants all self-identified as having chronic pain, their pain differed in origin, body placement, and severity. While seven participants were interviewed, only six transcripts were included for analysis. Although the excluded participant self-identified as having chronic pain and met the inclusion criteria of having their pain for more than three months, the participant's pain and management techniques were not at a level that they were helpful or could contribute to this study. The excluded participant happened to be the only male respondent. The analysis of this thesis is therefore only representing the data from the 6 female participants.

Design

Participant recruitment took place via social media posts on Twitter, word of mouth, as well as flyers around campus containing the contact information of the researcher as well as the certified REB number for this study. Once a potential participant contacted the researcher, the researcher introduced herself and the basic components of the study (See Appendix A). Providing the potential participant wished to continue with their involvement in the study, they were assessed according to the eligibility requirements. Were they to be found eligible for this study, they were asked for either their email or their mailing address in order to send them a

letter of invitation to the study and informed consent form (See Appendix B and C respectively). These forms detailed the participant's right to voluntarily withdraw from the study at any time, the main purpose of the study, the procedures used to collect data with the study, the method in which the researcher planned to protect the confidentiality of the participant, the known risks associated with the study, the expected benefits for the respondent, the REB file number, as well as the signature of the researcher and room for the signature of the potential participant (Creswell, 2013). This information was to ensure that the participant was fully informed of the potential benefits and harms associated with the study prior to making their decision of whether or not to participate. After the participant contacted the researcher to confirm their desire to participate in the study, the researcher scheduled an interview time and provided the participant with a map of Brock University (See Appendix D). Once an interview time was agreed upon, the researcher sent the potential participant a letter of confirmation (See Appendix E).

All interviews took place at Brock University, with six out of seven interviews taking place in the Qualitative Research Laboratory, located in Welsh Hall 145. This room is isolated from the rest of campus, with only one window, which remained covered for the duration of the research study. This provided privacy for the participant and fostered a safe space. Participants that drove to the study, were instructed where to park, and to remain in their vehicles for the researcher to escort the participant to the study room. There, they reviewed the informed consent form together, and the participant was once again reminded that they were able to withdraw their voluntary consent and choose to leave at any time. Voluntarily signed consent forms detailing the purpose of the study were mandatory prior to the commencement of every interview. The interviews were one-on-one and semi-structured, based off of an interview guide created with a refinement protocol (See Appendix F) (Castillo-Montoya, 2016; Creswell, 2013). This method of

interview allowed room for the participant to control the discussion and focus on their true meanings, rather than the interview being controlled by the researcher. All interviews were audiotaped with recording equipment, and then transcribed verbatim. This information was filed under a pseudonym to protect the confidentiality of the participant. Once transcribed and filed, these transcripts and tapes were stored in a locked filing cabinet located in Welsh Hall 145 and on a password protected laptop only accessible by the researcher. The laboratory is a secure room, with a lock on the door, and a covered window, to protect the confidentiality of the participant. The only people with access to this room were the principle investigator (PI), Dr. Maureen Connolly and the researcher, Rachel Richmond. Both members have completed and uphold the guidelines advocated in the TCPS-2: Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans. Following every interview, the researcher secured the room and escorted the participants back to their vehicles and provided them \$20 for their time. The researcher then returned to the lab and wrote field notes regarding non-verbal communication of the participant throughout the interview. These field notes were also stored as data to be reflected upon later, in the analysis stage. During that time, the researcher also journaled their observations and experience of the interview to be debriefed at a later time by the PI. In between interviews, a surface level, qualitative thematic analysis was conducted in order to further expand the researcher's knowledge and to adjust the approach to the following interviews. All major analyses were reviewed by both the researcher and the PI as an iterative process. This process was used to adjust the interview guide in order to focus the participant to yield more meaningful data.

Data Analysis Procedures for the Interview Phase

The analytic strategy implemented was that of Amadeo Giorgi's descriptive phenomenology. This method uses five steps to determine and describe the essential meanings that people in Ontario ascribe to their chronic pain. The first step was to read the transcript as a whole repeatedly, in order to understand the data from a holistic approach. This step was completed while the researcher adopted a transcendental phenomenological attitude. The second step was to re-read the data and separate the description into smaller sections called meaning units. These are components that describe essential attitudes of the participant in their own words. The third step involved transforming these meaning units from the words of the participants into expressions relevant to the field being studied and the phenomenon without implementing jargon. The fourth step in the method was to write an essential structure of the experience. To accomplish this, the researcher compared and contrasted the transformed meaning units from the third step to determine if they came from the same experience, making the structure generalizable. The final step was to synthesize the meaning structures into a statement that represents the experience being studied (Giorgi, 2009, 2012). For an example of how these 5 steps occurred within this thesis see Appendix H.

Strategies for Validating Findings

Due to the nature of qualitative research, the researcher underwent steps to ensure the validity and trustworthiness of both the data and results for this study. To ensure the validity of the findings, debriefing acted as an external check for the research process (Creswell, 2013). This process involved peer questioning and validating the project as well as the researcher. By

constantly asking questions regarding the methods, meanings, and interpretations, the honesty of the researcher throughout every stage of the research project was ensured. Another method used during this project to ensure its validity was ensuring rich, thick description (Creswell, 2013). Using this form of description allowed for readers to evaluate portions of the data as well and validate the findings of the researcher for themselves. Providing adequate thick description was provided, readers are able to transfer the concepts described to their own experiences. If these experiences are transferable, the researcher's findings will be validated (Lincoln & Guba, 1985).

Rigor was upheld for this thesis by implementing member checking (Smith & McGannon, 2018). Following the transcription of each interview, an email was sent to the associated participant including their transcript (See Appendix G), at which point, participants were instructed to comment, expand and ask questions regarding their transcripts. This provided participants with the opportunity to add to or clarify their content. Once the participant read and contributed their input, they were asked to report whether they thought the data provided captured their feelings and experiences of chronic pain self-management, ensuring the validity of the findings. Communication between the researcher and participants continued until the participant was able to confirm the accuracy of the data, ensuring that the subjective bias of the researcher was not present. The reliability and credibility of this data was ensured by transcribing each and every interview verbatim, member checking, and following Giorgi's analytical method. The findings of this study were found credible as no information was lost throughout the transparent and detailed analytical steps taken by the researcher.

Chapter 4: Findings

This chapter will demonstrate the delineation of self-management and its related terms and the inductive framework of analysis for six participant interviews. The manner in which my findings will be presented will be in four sections. In the first section, the data from the literature search on definitions of self-management and associated concepts were delineated, and definitions were formed and converted into plain language. The second section details the within interview salience for each participant, as well as repeating commonalities, called patterns. The third section outlines cross comparison patterns per question for all participants in clusters. Finally, in the fourth section, themes are presented that were generated from the saliences and patterns within the clusters.

Section 1 – Delineation of Self-Management and Related Terms

The raw data from which these descriptions and definitions are based can be found in Tables 2-4 in Appendix I.

Self-Help/Self-Help Groups

The degree to which the professional is involved varies across the self-help literature (Bachem & Maercker, 2016). It is categorized on a spectrum from ‘pure’, unguided self-help, to guided or supported self-help. Pure self-help is described as a self-administered therapy (Blankers et al., 2011; Levy et al., 2016; Pratt, Halliday, & Maxwell, 2009). The materials or information technology are provided alone to the participant with no facilitation or contact from a professional of any kind, at any point in time (Blankers et al., 2011; Hay, Bacaltchuk, Stefano, & Kashyap, 2009; Khan, Bower, & Rogers, 2007a). Moving away from ‘pure’ self help, there is

a continuum of how involved the professional can, or should be in one's care, and in what capacities. Hay and colleagues (2009) describe unguided self-help as being provided without any guidance from a professional, yet the individual still has some contact with the treating professional in cases where medication is involved. This can also be described as 'minimal contact' self-help, where minimal guidance is provided by the therapist (Greenwell, Sereda, Coulson, El Refaie, & Hoare, 2016). Any, and all contact with the professional occurs through either the phone or email, rather than in a traditional face-to-face therapist interaction (Greenwell et al., 2016). Norman and Ryrie (2013), detail that the role of the professional in self-help, should occur at the assessment and reference referral stage, and then only minimally, if at all, after that point. The furthest end of the continuum is supported self-help. This entails self-help resources which are used in parallel to individual sessions with the treating professional (Levy et al., 2016). The most used methods of self-help interventions occur in the middle of this spectrum, in which self-help resources are delivered with minimal and limited therapeutic contact to be fulfilled by the individual (Pratt et al., 2009; Varley, Webb, & Sheeran, 2011).

Regardless of the amount of professional contact involved in an individual's self-help regime, the literature details another non-therapist form of self-help, known as self-help groups. These are described as individuals that share a common experience, who voluntarily gather regularly to offer mutual support, and discuss potential solutions to their common issues (Jackson, Gregory, & McKinstry, 2009; Ketelaar et al., 2014; Norman & Ryrie, 2013). These groups form a social community, either physically or virtually, and consist mainly of talking therapy, empowering activities, sharing information, advice and raising each other's self esteems (Jackson et al., 2009; Pratt et al., 2009). Examples of topics that are discussed include: personal strategies of how to handle their common problem, the positives and negatives to medication,

correct dose of medication, exercise habits, spiritual beliefs, financial resources, hobbies, etc. (Pratt et al., 2009). These groups can run independently of professionals, may have a relationship with professional service, or can be assisted by community professionals (Jackson et al., 2009).

Whether one engages in pure self-help, guided self-help, and/or self-help groups, there are overarching characteristics that appear throughout the literature, as to what self-help truly is. Self-help is a stand alone program often based around a specific issue, condition or illness (Blankers et al., 2011; Norman & Ryrie, 2013). It is client-administered and is done for themselves, whether this is done alone or with support (Levy et al., 2016; Norman & Ryrie, 2013; Wilson & Zandberg, 2012). The program itself is flexible in its nature; meaning that the resources should be accessible from one's own home and at their own pace (Bachem & Maercker, 2016; Greenwell, Featherstone, & Hoare, 2015). These external resources can take a myriad of forms including: written materials such as books, manuals, information booklets, audio and video materials, computer and internet based materials or forums, smartphone applications, etc. (Greenwell et al., 2016; Khan et al., 2007a; Levy et al., 2016; Wilson & Zandberg, 2012). By implementing these resources in a flexible fashion, these programmes reduce common treatment barriers such as cost, stigma, transportation, child care, etc. (Bachem & Maercker, 2016; Greenwell et al., 2016; Rash & Petry, 2014). With the improved access for these programs over standard treatment, self-help acts as a means to remove much of the pressure placed upon specialists and relevant professionals, leaving them with more availability for patients with more severe or demanding needs (Greenwell et al., 2016; Pratt et al., 2009). These programs should however be developed and recommended by relevant professionals (Ketelaar et al., 2014; Norman & Ryrie, 2013; Pratt et al., 2009). The origin of self-help is unclear from the results of this search, however, the techniques are mostly derived from

cognitive behavioural therapy (CBT) and in some cases from motivational interviewing (MI) (Ketelaar et al., 2014; Khan et al., 2007a; Levy et al., 2016; Pratt et al., 2009). While each and every self-help program is different, many incorporate some tasks or activities for the participant to engage in, whether they are overarching tasks, or a step by step treatment protocol (Blankers et al., 2011; Greenwell et al., 2015; Pratt et al., 2009; Wilson & Zandberg, 2012).

Within this search, the purpose of self-help fell under three categories: education, skill development, and empowerment (Lintvedt et al., 2013; Norman & Ryrie, 2013; Pratt et al., 2009; Wilson & Zandberg, 2012). Wilson and Zanderberg (2012), Ketelaar et al. (2014), and Hay and colleagues (2009), explain that self-help is intended to educate individuals about their specific conditions. This category is meant to further inform persons of the intricacies of their diseases and allow the person to be their own advocate in relation to their health towards medical professionals as well as their surrounding community. Other researchers describe self-help as a manner in which to improve one's skill development (Lintvedt et al., 2013; Wilson & Zandberg, 2012). These skills are designed to assist in overcoming problems and symptoms regarding a specific condition (Wilson & Zandberg, 2012). These skills can vary from tactile skills, such as improved ability to test one's blood sugar levels, to psychological skills, such as improved mindfulness, attitude, coping, and self-efficacy (Lintvedt et al., 2013; Wilson & Zandberg, 2012). Self-help is also described to be a motivational and empowerment tool (Faulkner & Ryrie, 2009; Greenwell et al., 2016; Norman & Ryrie, 2013; Pratt et al., 2009). Self-help within this category is intended to encourage persons to make changes in their life and decrease their social isolation (Faulkner & Ryrie, 2009; Lintvedt et al., 2013; Norman & Ryrie, 2013; Pratt et al., 2009). These categories, however, overlap, and self-help rarely exists solely within one specific category (Lintvedt et al., 2013; Pratt et al., 2009; Wilson & Zandberg, 2012). Overall, regardless

of category, self-help is intended to decrease negative mental health consequences in a non-judgemental and flexible environment (Ketelaar et al., 2014; Pratt et al., 2009; Varley et al., 2011; Wilson & Zandberg, 2012).

Self-Care

There are many definitions within the literature for self-care; however, the two that appear to be the most recognizably used are from Dr. Dorothea Orem and the World Health Organization (WHO) (Orem, Taylor, & Renpenning, 1995; World Health Organization, 1983). Orem explains that self-care consists of the activities that individuals initiate and perform, consciously, by themselves, for themselves, repeatedly, to maintain their life development, health and wellbeing (Orem et al., 1995). The WHO describes self-care as the activities that families and communities perform for the purpose of enriching health, preventing disease, limiting illness, and restoring health (World Health Organization, 1983). While both of these explanations for self-care are actively used and share many commonalities, they also have significant differences. The main difference between these two definitions is the degree to which you are alone in your care. The most common point of view between researchers is that self-care must be performed by the individual, for themselves (Blickem et al., 2011; Cameron, Worrall-Carter, et al., 2010; Høy, Wagner, & Hall, 2007; Nolte & McKee, 2008; Norman & Ryrie, 2013; Rodríguez-Gázquez, Arredondo-Holguín, & Herrera-Cortés, 2012; Strachan, Currie, Harkness, Spaling, & Clark, 2014; Wilson, Baker, Nordstrom, & Legwand, 2008). Other researchers include the support and inclusion of a relevant professional into an individual's self-care (Aboagye, Karlsson, Hagberg, & Jensen, 2015; Albert, 2008b; Høy et al., 2007; Nolte & McKee, 2008; Srinivas et al., 2017; Strachan et al., 2014), while some specify that the one's surrounding

community of family and friends are also involved in one's care (Baydemir, Özdamar, & Ünalır, 2013; Nolte & McKee, 2008; Norman & Ryrie, 2013; Strachan et al., 2014). Within the literature, self-care is most commonly referred to as either an action or task (Cameron, Ski, & Thompson, 2012a; Nolte & McKee, 2008; Richard & Shea, 2011a; Rodríguez-Gázquez et al., 2012; Strachan et al., 2014; Wilson et al., 2008), the ability to make proper decisions (Nolte & McKee, 2008; Richard & Shea, 2011a; Strachan et al., 2014), and to change one's attitudes and behaviours (Cameron, Worrall-Carter, et al., 2010; Peters-Klimm et al., 2013; Rhoades, Telliard, Thomas, & Barkin, 2016a; Strachan et al., 2014).

While minor differences are expected amongst such a large body of literature, the term self-care is accompanied by blatant discrepancies with its definitions. The most obvious inconsistency lies with the debate as to whether self-care involves the utilization of pharmacopeia products (Robyn et al., 2012), or the contrary, whether only non-pharmacopeia products make up self-care (Cameron et al., 2012a; Kang, Himmelfarb, et al., 2015; Peters-Klimm et al., 2013). Other discrepancies exist within the desired purpose of self-care such as, in some cases, researchers state that it should be a preventative measure, and/or should be used for all populations prior to contracting a chronic condition (Cameron, Worrall-Carter, et al., 2010; Cameron et al., 2012a; Nolte & McKee, 2008; Norman & Ryrie, 2013). While it is elsewhere described to be for maintaining/sustaining life and health in whatever capacity the person is in (Alligood, 2014; Cameron et al., 2012a; Nolte & McKee, 2008; Richard & Shea, 2011a; Wilson et al., 2008), while others describe development and enhancement in one's current health status (Cameron, Worrall-Carter, et al., 2010; Cameron et al., 2012a; Norman & Ryrie, 2013; Peters-Klimm et al., 2013; Richard & Shea, 2011a). However, these categories rarely exist separate from each other, and many definitions describe a combination of these purposes (Blickem et al.,

2011; World Health Organization, 1983). For example, the WHO states that self-care is meant to encompass all three categories; to prevent disease, limit illness and to restore/enhance health (World Health Organization, 1983).

Self-Management

The main purpose of self-management is to manage one's symptoms in association with a condition (Barlow, Cooke, Mulligan, Beck, & Newman, 2010; Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002; Nolte & McKee, 2008; Norman & Ryrie, 2013; Richard & Shea, 2011b; Schulman-Green, Jaser, Park, & Whittemore, 2016; Solomon, Wagner, & Goes, 2012). Self-management is meant to control symptoms of psychological (Nolte & McKee, 2008; Norman & Ryrie, 2013; Richard & Shea, 2011a; Richards, 2004; Schulman-Green et al., 2016), physical (Barlow et al., 2002; Nolte & McKee, 2008; Norman & Ryrie, 2013; Sadler, Wolfe, Jones, & McKevitt, 2017), and emotional (Barlow et al., 2010; Jones, McKevitt, Riazi, & Liston, 2017; Jones, Riazi, & Norris, 2013; Martin et al., 2010) natures. The most common methods of self-managing are by actively making decisions regarding one's care (Barlow et al., 2010; Jones et al., 2013; Martin et al., 2010; Norman & Ryrie, 2013; Richard & Shea, 2011a; Richardson et al., 2015), and by changing one's behaviours (Barlow et al., 2010; Barlow et al., 2002; Jones et al., 2013; Norman & Ryrie, 2013; Richard & Shea, 2011a; Sadler et al., 2017; Schulman-Green et al., 2016). The most common definition of self-management is that of Barlow and colleagues, which states that self-management is "the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic condition" (Barlow et al., 2002). Barlow continues to explain that self-management is most effective when one is able to "monitor one's condition and to affect the cognitive,

behavioural, and emotional responses necessary to maintain a satisfactory quality of life” (Barlow et al., 2002).

Self-management is often reported in the literature to be for the illness population, or for persons living with a chronic health condition (Barlow et al., 2010; Barlow et al., 2002; Jones et al., 2013; Martin et al., 2010; Nolte & McKee, 2008; Norman & Ryrie, 2013; Richard & Shea, 2011b; Richardson et al., 2015; Schulman-Green et al., 2016). The act of self-management is mostly reported as something that must be completed by the individual themselves (Foster, Taylor, Eldridge, Ramsay, & Griffiths, 2007; Jones et al., 2013; Kennedy et al., 2013; Kenning et al., 2015; Klippel, Stone, & White, 2008; Laxy et al., 2014; Nolte & McKee, 2008; Norman & Ryrie, 2013). However, some researchers claim that self-management is meant to involve relevant professionals (Lim, Chan, & He, 2015; Norweg & Collins, 2013; Riekert, Ockene, & Pbert, 2013; Sadler et al., 2017; Solberg, Steinsbekk, Solbjør, Granbo, & Garåsen, 2014), and to involve community members (Bal et al., 2016; Lau-Walker, 2009; Lim et al., 2015; Richard & Shea, 2011b; Satink et al., 2016; Savage et al., 2011; Schulman-Green et al., 2016) as a part of one’s care. The majority of definitions described this additional involvement simply, as emotional support for the individual, rather than as an active component in one’s care, although that example is still present in some definitions of the term (Bal et al., 2016; Barlow et al., 2010; Sadler et al., 2017).

Definitions

Self-Help is the utilization of psychological treatments via external resources, in a flexible manner with minimal to no therapist contact, which may be derived from CBT or related theories. Self-help offsets the cost of healthcare and the time of professionals, by empowering individuals, educating them regarding their condition, encouraging healthy behaviour changes and developing skills to enhance their overall wellbeing.

Self-Help Groups involve the gathering of willing lay-participants surrounding a condition either physically or virtually. During regular meetings, members that possess this common condition will share their personal experiences, provide information, advice and mutual support to other members, as well as the potential for participating in voluntary wellbeing activities, such as exercise. Though no professional presence is necessary, self-help groups often have connections with associated local services.

Self-Care encompasses the activities that one performs themselves in order to maintain their health, limit illness, prevent new diseases and to improve mental, physical and emotional health.

Self-Management is an individual's ability to handle the symptoms of their condition and limit illness progression, by means of adopting lifestyle changes, activities, and decision-making skills in order to mitigate physical and psychological consequences inherent to living with a chronic condition. Self-management involves the completion of regulatory activities of daily living (ADL), and may require the assistance of a professional, and/or community support.

Coping is the manner in which one is able to utilize their cognitive and behavioural abilities in order to manage and overcome the internal and external demands of a stressful event. This event may be due to physical, psychological or environmental risk.

Patient-Driven Health Care is any form of care customized to fit the health needs and desires of an individual, consciously or subconsciously, taking into account one's desired level of responsibility, current health status, personal preferences, personality, context, history, social economic status, as well as individual strengths and weaknesses.

Plain Language Definition

Self-Help is using any resource that empowers, educates, reduces mental health challenges, and/or encourages someone to be healthier.

Self-Help Groups are small groups of people that share an experience or illness. They meet regularly, virtually or physically, to support each other, share their stories, and give each other advice. These groups may also participate in healthy activities together outside of their meetings, such as exercising.

Self-Care is anything someone does to maintain or improve their physical, mental or emotional health, for example, mindfulness, taking a bath, or exercising.

Self-Management is someone's ability to handle the negative effects that come with living with a chronic condition. It usually means changing their lifestyle and making decisions based on their condition, so they can live a better life. This can mean carrying out activities of daily living, such as eating to survive, or in some cases, it may involve hiring someone from the community to help them with those activities such as bathing regularly.

Coping is how someone reacts to a stressful situation, and then how they handle it.

Patient-Driven Health Care is anything a person does or is willing to do to take control of and improve their health. This kind of care is customized for the individual, based on their personality, preferences, and history.

Relationships Between Concepts

Patient-driven health care, as seen in Figure 1, is the overarching umbrella term in which all other terms fall. This indicates that all of self-care, self-management, coping, self-help and self-help groups are initiated in some manner by the individual. This model was created specifically for this study and this population. It was generated from the statements of consensus within each term's definitions within the literature, and then was influenced into its final form by the chronic pain participants. While it can be transferable to other groups, it was not intended to be overgeneralized.

Self-care is a primary concept which encompasses self-management and coping. While not every definition takes into account the desired population of self-care, throughout the literature there is some debate about who self-care is intended for. Some state it is for the illness population suffering from a chronic disease or condition (Berzins, Reilly, Abell, Hughes, &

Challis, 2009; Blickem et al., 2011; Cameron et al., 2012a; Hudson et al., 2016; Srinivas et al., 2017), while others state that it is meant for all populations, intended to be utilized by healthy people, in the absence of any condition (Høy et al., 2007; Manzini & Simonetti, 2009; Mawson et al., 2014a; Nolte & McKee, 2008; Rhoades et al., 2016a). In the majority of cases of self-care within the literature, the term is used in relation to an individual with a health condition and describes self-care as ADL (Barbaranelli, Lee, Vellone, & Riegel, 2015; Berzins et al., 2009; Kang, Dennison Himmelfarb, et al., 2015; Nolte & McKee, 2008; Richard & Shea, 2011a; Strachan et al., 2014). However, these attributes more commonly fit under self-management. Self-care is meant for all populations, while self-management is a subset intended for individuals with a condition. This finding is consistent with that of Richard and Shea (2011). Coping exists within both self-care and self-management, as they are both situation specific, and involve a reaction and action phase.

While self-care is situational, self-help is resource based. These terms are quite different, and yet, they are not without commonalities. Both are meant to alleviate the pressures on the health care system. By having individuals care, manage and help themselves outside of the structured healthcare system, both time and money is saved on the side of the professionals. Self-help is typically meant as an alternative to formal therapy, in which the individual works through external resources at their leisure. Self-help groups exist virtually or physically as a living resource within the larger concept of self-help.

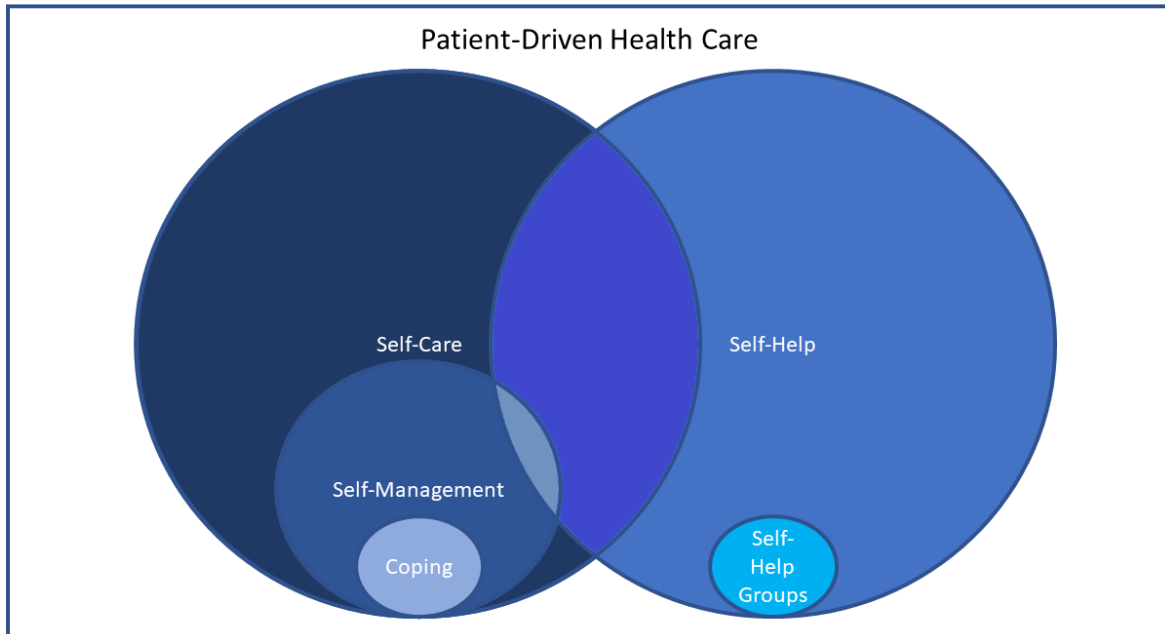


Figure 1. Conceptual Model

Section 2 – Within Interview Salience and Pattern

All interviews were transcribed verbatim and then read individually multiple times. This allowed the researcher to immerse herself into the data of each interview and understand them as a whole. Following this immersion, the transcript was re-read in search for salience and then again for pattern. This section demonstrates that salience and pattern for each participant using their pseudonym.

Laura: This participant is a 23-year-old female who has lived with rheumatoid arthritis and an undiagnosed digestive chronic illness for approximately ten years. She has an emotional support system in place, but physically manages her pain alone.

Saliency: A key point made was that chronic pain is a significant part of Laura's life. She states that it is on her mind approximately 70% of the time, overpowering her thoughts and conversations. It impacts her physically, psychologically, emotionally, and socially. She described her pain and her doctors being in control of her lifestyle choices, and that her wants and preferences were unimportant. Laura stated that she was forced into a position in which she could choose "health or life". To follow the physicians' words exactly or, to alter her own course of treatment to suit living a life. She said it best when she said:

My preferences don't really matter; between what my body wants and what my doctors wants for me, what I want doesn't mean anything.

However, the power struggle is not only between Laura and her physicians, but her pain as well. Her condition dictates her social interactions and over time, she has adjusted her personality to yield to it. She has missed out on many social events and meaningful experiences with her peers, and each time she told herself that the event wouldn't have been fun anyways, in order to try and convince herself that she hadn't missed out. Ultimately, this resulted in her having a dismissive and isolated personality, to the point at which she no longer wanted to make plans with her peers for fear that her pain would force her to cancel them. These feelings are demonstrated when she said:

Having chronic pain makes it hard to have a social life. Like my personality uh, I find I'm so dismissive. Like I'll say to myself 'Oh, I'm not feeling good enough to go out today, that's okay I didn't want to go to that party anyways'. Like I've gotten to the point where I find myself pushing those urges to want to go out or to want to be sociable, and

kind of adapting to it mentally so its more okay in my mind so I'm not as hurt and I'm not so... I don't feel so isolated.

When her chronic pain began, Laura described her pain as debilitating and all consuming, to the extent that she was unable to walk down a hallway without assistance. Over time, through lots of online research, listening to what her body needed, and trial and error, she has regained some of her independence. While she has made strides towards being able to live with chronic pain more comfortably, she still experiences daily struggles and major lifestyle changes. Her struggle is evident when she said:

Like sometimes I'm just curled up and crawling because I'm in so much pain, but I've got a heat pack on and, and that's um, what I use to self-manage my pain.

Even after a decade of living with chronic pain, whenever it flares up, she still feels self-conscious and won't relax until she is 'safe' and isolated in her own room. Once there, she applies heat packs and drinks hot tea to ease the pain somewhat and to calm and soothe herself. Those strategies originate from her upbringing and remind her of home, where she originally felt safe, these feelings are reflected when she stated:

I usually just try to get home, um, or I try to get to a spot that I can just like crash for two hours and kind of cope with it on my own. Like, I'm a very private person, so just like experiencing pain in public, I feel like everyone is staring at me, like I feel like everyone knows and is like what is wrong with you. So, um, I try to isolate myself it's the only way I kind of deal with it. [...] I always try to get back home and get back into my safe bed.

Along with the social and physical impacts on Laura due to her chronic pain, there are also emotional impacts. Laura is a 23-year-old female with a fit and healthy-looking build. She reported that many people doubt her claims of truly being in pain and sometimes needing accommodations because she doesn't look 'sick'. They assume that she is making up excuses because she is lazy rather than due to her chronic pain. This makes explaining herself and her situation to new friends, colleagues and supervisors very difficult, especially without a diagnosis. Unfortunately, the alternative is also true, where some employers started to pity her and made her feel less than capable due to her pain. All of these emotions were brought to light when she said:

A lot of people think of it as I'm faking because they don't see, um, they don't see it. I just look like a regular 23-year-old. [...] Its like new [superiors] really don't understand, um, you always have to explain your story even if you don't have a diagnosis. Um like its so hard starting new [jobs] and stuff like that. You have to walk in and say, 'I'm sorry but this is what I have to face in my day-to-day life'. So sometimes you feel like they're pitying you or sometimes its like 'oh she's not as capable as we thought'.

Laura also discusses being in a limited state. While she is capable of doing many of the things common for a person at her stage in life to be doing, she knows that there is a limit. She details simple things that her peers take for granted that she is unable to do, such as having impromptu sleepovers, having a long meal with friends, going to the gym for an extended period of time, etc. This limited state also extends to her aspirations and plans. While her peers are

planning to go on exciting trips, Laura acknowledges that those types of plans are unrealistic for her, which she described when she said:

I know I'll probably never be able to travel. Like you see everyone going backpacking and being like that's not realistic for me when its tiresome to walk to the grocery store.

She works on accepting her condition and her current limitations, but also carries fear for the future. Within the same quote, Laura explains how she longs for a 'normal' life, that she accepts her current limitations, and fear of future limitations, as are apparent when she said:

There's so many things that I would want to do that I see my friends doing. Um, it's not possible, anyways its just not a possibility for me. So, I kind of just have to accept that. [...] I'm um, just like half living life, if that makes sense, and constantly wondering, 'Okay, at what point will I not be able to go to the gym at all' um, and kind of preparing for those future changes, those declines.

Pattern: Throughout the interview, Laura repeatedly demonstrated her main coping mechanism to living socially with chronic pain. She convinces herself that she does not want to participate in social activities that all of her peers are interested in. By doing this, she hopes to be able to handle and accept the situation, should her pain stop her from attending. Another pattern that appeared repeatedly within the interview was the participant's lack of control. This lack of control is the result of both her physicians and their treatment plan for her, and her chronic pain itself. Laura described being put in the position to choose health or life, and then was berated for daring to make a choice. This demonstrates that she only has perceived control, not real control.

Laura's pain also often causes her to avoid making plans or to cancel plans that have already been made, which deeply impacts her social life, further instilling the concept that she has no control over her lifestyle and that her preferences don't matter.

Sofia: This participant is a middle-aged, retired, married woman, living with chronic knee arthritis for approximately five years.

Saliency: Within this interview, Sofia expressed feeling limited. Her pain limits her mobility, which affects many aspects of her life. In the physical aspect, she is limited by the distance and terrain combination in which she is able to travel. Which she explained when she said:

It's very limiting with, for some of the things I have historically liked to do. Um, my, my pain is pretty much in my joints, it's arthritic so walking is difficult, any kind of distance is impossible, climbing stairs is hard. Um, it's, it's being limited. No endurance. You know I might be able to climb you know 20 stairs, but then there won't be any stair climbing for the rest of the day.

In order to conserve her theoretical movement reservoir, her husband and mother often take on the burden of climbing stairs or walking around the house to retrieve things for her.

My husband is very encouraging to sort of help me. He will, he will go and get me drinks and rather than use up some of those spoons. So, he will take off some of the burden of running up and down the stairs. My mother does that as well.

These limitations also affected Sofia at work. She was unable to complete many of the tasks required of her in the later years of work prior to her retirement, due to her pain.

It's more about limitations. Is what I tend to think about. Um, I, I've been very fortunate in that um, I was able to retire from work um, last year. For the last, probably 3 years at work, there were parts of my job that I was completely incapable of doing, because I could not haul things around. I could not, you know, carry around all of the things I needed to, to set up displays. So, trying to find ways of dealing with that in the workplace was very difficult.

To mitigate this, Sofia must ask for accommodations, which she doesn't like to do because it makes her feel 'less than'. Sofia struggles between accepting the pain herself and asking for these accommodations.

Um, having to ask for accommodations is a difficult thing to have to do. I don't like feeling less than or feeling limited, um, when I am asking for accommodations that I am fully within my rights to receive. It is an imposition upon other people, it does make their life more difficult, and I don't like doing that. So, it becomes much more of a suck it up and do it.

Sofia also discusses her pain limiting her desired activities. She mentioned that prior to her pain she had little desire to jump on a trampoline or drive a skidoo, yet now that those activities are no longer available to her, she feels limited that they are no longer options for her participation, as indicated when she said:

'I guess I'll never be able to jump on a trampoline again'. Which is one of the, weirdly that's one of the things that I actually miss. I don't want to jump on a trampoline, I have not jumped on a trampoline since I was a teenager, but now I look at trampolines and that sky zone place or people that have trampolines in their backyards and I'm like [whines]. You know. [laughs] I don't want to drive, to go on a skidoo, or sea-doo or whatever those things are called. [...] I have friends that have both of those things. I've never had any interest in going on one, but now I bemoan the fact that I can't.

Chronic pain is a complicated and unpredictable problem which makes it quite difficult for participants to discuss and manage. As there is no one way to find relief from chronic pain, Sofia has undergone trial and error to find some strategies that work for her and has also discovered some that do not. For example, she finds that ceasing her current actions or changing positions can sometimes alleviate her pain.

Well, there's the whining and complaining, but that isn't really particularly helpful. [laughs] Um, so I do that, and then I stop whatever it is that I'm doing, and if it goes away, great, then I know that stopping it helped and if it doesn't go away then I work on pain relief. Whether it be, you know, cold compresses, hot compresses, um, you know medication, whatever. Sometimes position changes help. So, I will work on relieving that.

When that is not the case, she often resorts to either cold or hot compresses and medication. Should the pain persist, Sofia will continue to try different things including distracting herself or causing herself pain in another part of her body to make her stop thinking about her original pain.

You know, I might need to, basically, I keep trying different things until something relieves the pain. So far, I haven't had to resort to anything really stupid, but, you know, um, basically hitting it, things like that [...]
It feels better. It's sort of like the theory um, you know, 'damnit my hand is hurting its like well, you know whack your head on the wall a few times and your hand won't hurt anymore'. [laughing] It's not really the same thing but distraction.

She also discussed exercise as a manner to strengthen her muscles and alleviate pain, yet this comes with some negatives. While exercise sometimes helps, it can also make the pain worse. There are also inherent contradictions with pain for Sofia. Some contradictions are evident when she stated both:

Don't stop at the first twinge of pain, and kind of go 'oh well...' you know, just keep at it... don't become so self-limiting. That's what I think.

As well as when she said:

Exercising through the pain has not helped. [laughs] I did actually try that at one point, and that was a very bad idea.

Further contradictions associated with her pain are that walking or moving too much depletes her energy and endurance, causing her to have to stop and rest often. However, staying in the same position for too long, causes her further pain. Which she described in this example:

So, you know when I wake up in the middle of the night and because my leg has been in the same position for 3 hours, and you know I can't move it. Then that's, that's a problem. The goal there is 'oh my g-d it hurts, I need to get up I need to move it around, I need to walk around for a few minutes'.

Pattern: Sofia repeatedly referred to her pain as limiting. She used this mostly in the physical context, however, many other aspects of her life seemed to be limited due to her pain. Another repeating pattern was the presence of contradictions. There appeared to be many conflicts for Sofia surrounding her pain. She reported knowing that weight loss would alleviate pain in her knees and yet, exercising to rid herself of the excess weight caused her pain. She also struggles with the conflict of whether to bare the burden of her pain, or to ask for accommodations, which she perceives as a burden on others. Another conflict Sofia experiences, is whether to rest and conserve her endurance or to remain moving and constantly changing positions to avoid excess pain but use up her reservoirs.

Sarah: Sarah is a 22-year-old female who has lived with chronic headaches and migraines for approximately two years.

Salience: Speaking about her pain was very difficult for Sarah and it brought up many emotions for her. Chronic pain is a predominant aspect of Sarah's life, with a constant ache that only increases throughout the day. Despite Sarah knowing and acknowledging the she now lives with chronic pain, and that this is her new normal, she still tries anything and everything she can to find moments of temporary relief. Sarah lives for, and longs for these moments where she

could go about her life in the manner she did prior to the pain. Sarah used statements like this often throughout the interview to describe this feeling, such as:

I just wanna like feel normal, I wanna be how I was.

To achieve this, she opts for a trial and error approach which has led her to many strategies. Some of these strategies are fairly simple, such as stretching, hot/cold packs, massages, and meditation, etc., while others, such as numerous medications, Botox and nerve block injections, come with side effects and added problems. Sarah feels that even though these numerous side effects are unpleasant, if they manage to provide any relief from the pain, then they are considered worth it.

I get um, nerve block injections in my face, which I got just a week ago, so that's why I'm having like, a better week so, it's ah, it kind of lowers my pain for a bit. They're really painful, they're not uncomfortable, but that's kind of the trade off, it's hopefully having less pain, um, for a longer period of time. And you know, even if it's just a day, like to me that matters. Like if I can go a day feeling better, then I can get stuff done.

Unfortunately, there is not a singular management technique that always works for her. What may have relieved some pain one day, may make the pain worse on others. While Sarah's usual pain management technique includes going into her dark room, eliminating all screens, using a cold pack and laying down, some days, what helps is taking a walk outdoors, while talking to a friend or watching Netflix. Sarah's emotions towards her self-management techniques are reflected when she said:

This is my normal now so like I kind of have to adjust to it, and like, I mean like, it is a pain centered life.

Sarah's chronic pain also brought about noticeable fear. Not being able to predict the severity of her pain in the future, makes her weary of making plans or participating in social obligations for fear of having to cancel. She describes the toll on her social life when she said:

Like social life, going out, um, because it gets worse throughout the day, and just making plans in advance, I'm always like, I don't want to say yes, 'cause I'm like I'll see how I feel and like I want to of course, but, um, I'm like, I don't know, I can never really predict... unless if I start the day already waking up feeling awful, I know that like, it's just going to be a bad day.

This fear, however, transcends Sarah's social activities, and affects her in other manners as well. Sarah even describes this fear affecting her when she's experiencing a 'good' day, because it may not last, which is evident when she said:

I'm always just worried that like, it's going to get worse throughout the day, and that's kind of like, the fear, like I'm always like too comfortable.

She describes anxiety about her future due to her age, especially when confronted with people in a similar situation to hers, that are much older than she is. At that point, the reality of her chronic pain truly hits her, and she fears what her pain will do to her life. In reaction to this, Sarah chooses to delude herself into thinking that her chronic pain is only temporary, which is demonstrated when she said:

I try to just tell myself it's temporary, it's temporary, like, it's not permanent, I'm like you know, I've been in pain before and like maybe I can fix it.

Pattern: Within the interview Sarah repeated her mantra regarding her chronic pain, that it's only temporary. She speaks about accepting chronic pain as her new 'normal', yet her mantra of pain being only temporary conflicts with this ideal. To get through it, she relies on remaining organized and trial and error. While she is not ashamed or embarrassed about her pain, she doesn't share it with everyone for fear that they won't understand the severity of what she is dealing with. This fear is also related to her own feelings about her future. Sarah is a young adult and commonly associates chronic pain with older individuals. The fear that she might have to live with this pain for many years to come reinforces her mental outlook, that perhaps her pain isn't permanent after all.

Diana: Diana is a 21-year-old female living with chronic neck pain for the past 7 years. She previously experienced a trauma to her neck and it took months for doctors to properly diagnose and treat the break properly, resulting in her chronic neck pain.

Salience: Diana described many of the changes that chronic pain has brought to her life. It affects her socially by the manner in which she interacts and makes plans with her friends. Her pain often makes her cancel plans or leave events early, to mitigate this, she must make extra efforts to demonstrate how important her friends are to her, which she described when she said:

I used to cancel plans A LOT and it was like 'she's a flake', and I really hate that, so I try not to do that as much. And especially if I don't tell people and I keep like the 'why' private then they're just like 'She doesn't have a reason, she's just a flake, she's lazy', you know [...] I definitely try to make more plans even if I flake on those too, like I try to be more interactive with my friends, to like show them that, 'I do care, I'm trying'. Like I'm not... 'I'm interested in what's happening.

Chronic pain also affects Diana's personality. Prior to her pain, she was outgoing and talkative, whereas now, she is more shy, especially about her pain. She described these personality changes when she said:

I would say that I used to be more, I'd say more talkative, more outgoing, just more involved in everything, more out there, and I'm much more closed off and I guess shy now. [...] I don't have as many friends as I used to in high school because of the, my neck, because I'm just so self-conscious about it.

In addition to all of these pain driven changes, her familial relationships have changed. She explained that her accident and pain caused her to become much closer with her mother and her siblings, yet much more distant with her father. These feelings are represented when she said:

So, definitely when I was in the hospital and stuff, my relationship... my mom was in the hospital with me for the entire time. I didn't see her leave once. Clearly, I was sleeping a lot, but I didn't see her leave. And my brothers, when I came home, I couldn't sleep in my bed, so I had to sleep on the couch, and my brothers took turns every night sleeping with

me in the living room. So, that was like, and we grew closer. And my dad, he didn't like, see me in pain so like, just like the distance just changed the relationship completely [...] like, it's more of a business relationship, I guess.

Chronic pain is also accompanied by fear and anxiety for Diana. She discussed her pain being a major factor in large lifestyle decisions, such as where to go to school. Diana's plan was always to attend post-secondary education at a school close to home, however due to her pain, she chose to pursue her education farther from home. Her accident and subsequent neck pain was public knowledge to everyone in her relative geographical location, in order to avoid further pity and staring, the participant moved away to create a fresh start with brand new people. She described her motivations to move when she said:

So, I just thought for myself that it would be better to move away from that and get a new fresh start where, when people looked at me, I wouldn't be like 'oh they're thinking about me or my injury or my pain or thinking about how flaky I used to be or still am'. So, coming here was definitely better. Also like the pity, like, I didn't want the pity. That's probably why I'm like more private about it, because I don't want to be like 'pity me and be my friend', like [laughs]. So, I know who's my friend because of me, not because of what happened.

As this pain related lifestyle change was extremely significant to Diana, she also mentioned that moving away from her home town made her feel more safe. It allowed her the freedom to make new friends and be judged for who she is, not her pain. She described this change when she said:

I think I would've went to college closer to home, I wouldn't have branched out so much. So, because I wanted to get away from anyone that knew me with the neck issue. So, coming here, nobody knew, and it made me feel I guess safer in a way. So, that was kinda positive, and then coming here I also branched out with my confidence and everything, so I think that helped as well.

Not only did she move away from home to avoid prying eyes and knowing glances, but even in her everyday life, this pain related anxiety has a large effect. Diana keeps her pain private to avoid further pity and added anxiety. In this new city she has only opened up about her chronic pain to two very close peers.

What I've noticed is that um, with, when someone pays attention to me like, like zeros in on me, I get like twitchy, and I notice that, like I can tell that, that it hurts. And it hurts more when someone pays attention to me, so, people will be like 'oh, what is wrong with her...' like 'what is she doing'. So, I try to keep private like, um, I think people here [...] like my friends, only two people know.

When she experiences pain in public, her first reaction is to the surrounding people and her fear that they are judging her. In these situations, the participant often ceases any activity that she is participating in, and heads home to where she can shut down away from judgement and pitying eyes, which is reflected through the following statement:

I probably stress about it for a second, and 'I'm like there are so many people around', because like first off anxiety is a huge issue for me, which actually comes with a lot of chronic pain, um, and then I try to

massage, um, I do um, sometimes I'll just get into that mode where you're just like, I'm done, let me go home and just like, kind of shut yourself down.

Pattern: Within the interview Diana repeatedly expressed how much her chronic pain has affected and altered her life. This occurred through major life decisions, alterations to her personality, her ever changing social life, and changes to her familial dynamics. While these are some very large changes due to her pain, Diana does not view them all negatively. She has managed to find a positive outlook through her chronic pain and views some aspects such as growing closer with her mother and siblings, moving away from home, and branching out as a positive in her life that would not have happened if it weren't for her pain. Unfortunately, not all effects of her chronic pain are positive. She has developed increased anxiety related to her pain and social interactions. While she has some close friends that know about her pain, she keeps it a secret from everyone else. Should she experience pain while in public, she feels as though everyone knows, and is judging and pitying her. At this point, she tries to get home to where it's safe to break down and begin her trial and error to relieve the pain.

Olive: Olive is a 22-year-old female participant who has been living with chronic back pain for over eight years. Her pain originated as a childhood sports injury.

Salience: Olive expresses being psychologically affected by her pain. In spite of numerous doctors, X-Rays, various tests, medications, and treatment plans, she is continually told that she is healthy, and that her pain is not real. This leaves her to either doubt the words of

‘experts’ in the field of medicine and continue to advocate that her pain is in fact real and not all in her head, or she can doubt her own body and her own mind, issuing herself a psychological diagnosis. This battle has plagued Olive for years and has not gotten easier for her over time.

That’s basically been all my doctor visits. It’s like you go in, you tell them what’s the problem, they ask you a bunch of questions, you tell them how you’re feeling your pain, how the pain’s affecting you, how it sort of affected you, they run a couple of x-rays, and then they come back and then it’s nothing. That’s, you know, and then here’s a couple of medications. And it’s like ‘Okay, this is like the 15th doctor I’ve been to, thank you very much for telling me exactly what you’ve already told me’, you know what I mean.

She describes visits with her physicians in a negative light, such as when she said:

You go to the hospital and they’re like bam, bam, ‘Here’s medication. Why don’t you take it, it will make you feel better for like 3 hours and then your pain will continue’.

Living with chronic pain without a diagnosis is discouraging and psychologically taxing for her.

She expressed her desperate desire for a diagnosis of any severity, going so far as to say even if it meant she would die the next day, that she would rather know than remain in her current state.

This desire and desperation is expressed when she said:

It would be nice to get another outcome that isn’t already what I’m getting you know what I mean. Even if like the outcome isn’t something I want to hear. Like I want to go see, like I want to hear it, no matter

how bad it is, you know what I mean. Like, am I dying tomorrow, like I need to know?

Olive also describes both positive and negative experiences related to her pain. Her daily routine requires her to sit for extended periods of time with very few breaks, causing her pain to persist without any relief. Alternatively, many of her days also require extensive amounts of physical activity, which can be difficult on the body. While in most cases this may seem like a negative, Olive reported revealing her pain to her superior, resulting in her being able to skip the difficult activities. She reported these positives also affecting her outlook and she gave some examples when she said:

It gets me out of a lot of things that I don't have to do so [shrugging] there are positive sides to it, I guess. [...] I think if anything, the back pain has sort of been like a blessing in disguise as in terms of like its, it's sort of helped me explore other things about myself, other personalities, personality traits that I didn't know I had, have sort of emerged out of the pain.

On the other hand, if there is an activity that she likes but will likely cause her significant pain, she will push through and accept the pain, which is evident from when she said:

I know obviously, by the time I'm getting back at the end of the day I'm going to be feeling that pain, but like for me, it's worth it, because at least I would've done something with my day, you know what I mean. Um, even if it means that I have to feel the pain at the end of the day, that's what the muscle relaxers are there for, it's supposed to do its work, so I'm good.

As a young adult, her lack of resources limits her potential participation in many of the treatments and behaviours she believes could help her pain.

It's not, at this point there's nothing really, I can do. [...] Like it's just, you just have to, I don't know do whatever you can to sort of like relax yourself in that moment and like make yourself feel better. [...] Like, whether I'm dealing with it or not, its there.

Olive often prioritizes her time and money towards other aspects of her life, rather than towards her pain and/or the amelioration of it. This is evident when she said:

I don't have time to sort of like focus on it now, and as much as I like don't have time, I don't also have money. So, like, if you don't have money there's really nothing you can do. [...] I'm like I can't even afford food this week, and I'm going to physio... I think I can take the food over the physio. I'm just saying.

This allocation of resources, means that her self-management behaviours often consist of cheaper, relaxing, home-remedies, and different methods of distraction, which she described as:

It's more of just like home remedies, heating pads, medications and just like sleeping it off or like, sort of like relaxing, and watching a movie and stuff like that.

Pattern: Olive has had numerous negative interactions with health care professionals, in which her concerns are either ignored, or she is given medication that doesn't suit her lifestyle. She has been repeatedly placed in positions where she has had to justify the reality of her pain to

physicians and has been continually dismissed. These interactions have caused her to doubt herself and the authenticity of her pain. This has led Olive to consider if the physicians are right and the pain isn't real, but purely psychological, or if she is right and must remain her own health advocate. While her chronic pain does not stop her from participating in activities or how she interacts with others socially, she has found both positives and negatives associated with it. Olive's back pain gives her leeway in avoiding certain strenuous tasks, that she may not have wanted to perform in the first place, which she views as a positive outcome. Unfortunately, there are also negatives, in which she cannot afford to manage her chronic pain well. As a young adult, Olive is forced to choose between managing her pain or allocating her resources to food and rent. She often chooses the latter.

Nancy: Nancy is a middle-aged, married woman living with chronic pain due to a congenital spinal birth defect. While many surgeries have offered temporary relief in her past, her chronic pain has always returned.

Saliency: Throughout the interview Nancy outlined her difficulties associated with chronic pain. She detailed that it affects her mood, mental health, relationships, work, family life and overall mobility. While she explained that she was never overly athletic, potentially due to having this birth defect, she enjoys walking. Although, due to the recurring and devastating effects her pain has on her mobility, the long walks that she previously enjoyed turned into less than five-minute walks, and at times it was even a struggle for her to walk around her block which she described below:

Mobility wise, that means I trip a lot, right, and this foot doesn't quite work right. [...] The pain this time has been tremendous, tremendously worse than it's ever been... for the past two and a half, two years and a bit, since July 2016. So, that's the history of it, um, so it comes and goes, and I've had periods of mostly relief, right I think there's always some pain, but to the point where I don't notice it, and where I can, you know, lead a fairly normal life. I mean I've never been tremendously a physically active person, probably because of that, you know, but, I mean, I swim, and I, I walk a lot, right. Walking is good for back pain, um, but now I can't walk for more than five minutes and a week before this happened this time I had walked for like miles in a day at worst, like hours and then it went down to, oh gosh, at first, like I couldn't walk around the block, and now I can walk, I can walk up to like half an hour, 45 minutes if it's a good day, you know, on flat terrain, city walking.

This not only changes her leisure plans and affects her likelihood of travel, but her work life is also affected, as her position requires her to remain standing for extended periods of time, which is quite difficult for her. In times of extreme pain, Nancy's first reaction is to try and get home, if possible, and just lay down. For this reason, she has arranged that much of her work can be done from home, and that she has a couch in her office in case she needs a break. Once she is home, she has some self-management mechanisms already in place, such as medication, a place for meditation, relaxation, and many useful distractions. She describes her travel barriers and need to get home when she said:

When I'm out it's really tough and, uh, and so I get a taxi and I go home if it gets really bad. That's what I do, so I haven't been able to travel too much lately, when I can't travel without my husband, 'cause I can't carry anything that weighs more than a couple pounds and, but, I take advantage of things like wheelchairs in airports and that kind of thing, 'cause I can't stand for very long, that's the most difficult thing, is standing.

Nancy shared that she attends counselling sessions to assist her in handling the emotional strain that comes with chronic pain. Despite having a medical diagnosis, she described the difficulties of being heard, and taken seriously by medical professionals, such as when she said:

Because there are doctors that treat you as an object to be studied, and there are doctors that treat you as a human being.

Prior to her diagnosis, she was repeatedly dismissed by physicians that claimed she was only experiencing growing pains, and nothing more.

He just said, 'It's growing pains, happens to everyone, no big deal, don't worry about it'. He treated us like we were, in retrospect, like, just like, we were hysterical women, kinda thing. Um, he didn't take us seriously at all, and I know that's the experience of many women who have dealt with pain.

Fortunately, her mother became her advocate and sought out a specialist when Nancy was young, which led to her diagnosis and the following sets of painful surgeries. Despite the temporary relief that the surgeries brought her, she still required help with household chores from her

husband and family, which she reluctantly accepted. Nancy relayed her dislike for allowing others to help her, and also her observation that it hurts her family to see her in pain.

My husband's very helpful, he um, sort of does a lot of things that make it easier, you know like, he's taken over most of the chores at home, that kind of support, you know. Um, I still, I have a really hard time letting other people do things for me, it's a struggle, so I find that hard, um, but he's, he's trying.

While her family are excellent listeners and try to provide emotional support for her, she prefers to express and talk through her feelings about chronic pain with her therapist, to avoid added burden on those that surround her.

My parents, my mom, my dad have helped. They just listen to me, and my sister listens. Having people listen is really good, um. [...] I know it hurts them to see me in pain, um so, it's really tough. [...] I also go to a therapist once a week and I've found that that helps a lot, and then I can just sort of unload all of my feelings about it, and I'm not unloading it on someone close to me, and that sort of purging seems to help.

Nancy also discussed her openness regarding her pain. She views this transparency both as a manner of talking through her struggles with others that are in similar situations, and as a way to mitigate being the topic of hushed conversations. While she has access and does most of her pain related research via medical journals, she enjoys talking through her pain and strategies with her peers that have experienced similar issues. As she is a public figure, Nancy is very upfront regarding her pain, to avoid the spreading of rumours or having her health be the center of

attention. This is also a result of being stared at as a child and alienated for having to miss school to go to the hospital for extended periods of time, which she described when she said:

I'm open with friends, I'm open with my [subordinates], I tell them. I'm open with my [peers], I... because I think it's, then they're just going to be wondering 'Why is she acting so strangely' or sometimes I have trouble walking um, and so it's more visible um, sometimes I have trouble concentrating, stuff like that. So, I, I need people to know so they, 'cause otherwise they're just wondering and that goes back to that grade six, when you become like an object of everyone's gossip [laughs]. So, and I think you know, friends are supportive right, so... and I have other friends who've had similar issues so, it's good to talk to them.

Pattern: Throughout this interview Nancy demonstrated her ability to adapt to her chronic pain, through the use of her support systems, her research into her condition, her openness, and her paying attention to what her body needs. As her pain originated in childhood, many of her management strategies towards her pain were ingrained in her from her mother, such as touch and laying down. On the other hand, seeing her parents scared for her made Nancy feel as though she missed out on her childhood. When she returned from her stay in the hospital with a brace, Nancy also endured staring and isolation from her peers, which has led her to be open about her pain as an adult. As her pain fluctuates, she is careful to adapt to it, physically and emotionally. By limiting her exercise and taking advantage of services such as wheelchairs in airports, she is able to keep up with her body's physical restrictions. Emotionally, she ensures that she mediates

and discusses her feelings through both her therapist and peers that are undergoing similar experiences of pain.

Section 3 – Cross Comparison Patterns Per Question

This section will outline cross comparison patterns per question for all participants. As interviews were only semi-structured, not every participant answered each question. Here these patterns will be presented in information clusters.

Opening Question: How long have you experienced chronic pain?

Salience: 10+, 5, 2, 7, 8+, and 30 years.

Pattern: N/A

Cluster 1: Understanding the Effects of Chronic Pain

Question 1: How has your pain affected you physically?

Salience: Chronic pain affected each participant differently due to their type of pain and their individual lifestyles. Some participants were physically affected by limitations to their mobility, while in some cases it stopped others from participating in activities they enjoyed all together. In all cases, it was a significant ache that made the participants aware of their behaviours.

Pattern: Every participant was able to easily speak to how their pain affected them in a physical capacity. Whether it was explaining where their pain originated, or how it affected them and their decisions. The concept of being limited by their chronic pain was also touched upon by almost every participant.

Question 2: How has your pain affected you psychologically?

Salience: Not all participants were psychologically affected in the same manner, however, everyone reported being psychologically affected in some way. The young adult participants all reported a fear of the future with regards to their pain. Whether this referred to future declines, countless more years with pain, or fear of how their pain will affect future biological functions such as pregnancy. This fear for the future was not as apparent in the middle-aged participants, however, one expressed her fear of upcoming surgeries for her pain.

Pattern: The majority of participants brought up concerns of the psychological difficulty of not having a diagnosis. The concern of having pain and not knowing its origin or not being believed, takes a psychological toll. Participants also expressed the psychological burden of asking for help and being pitied due to their pain. To this effect, many participants reported keeping their chronic pain private, and only informing those closest to them. Many participants also conveyed that their personalities and mood have changed due to their pain, whether positively or negatively.

Question 3: How has your pain affected you socially?

Salience: Many participants found that due to their pain, they cancelled plans frequently with their peers, and in some cases, they avoided making plans altogether to avoid the potential situation that their pain could ruin the activity. While chronic pain typically had a negative effect

socially on participants, some were able to find positive social outcomes from it as well. It was also reported that having chronic pain altered many relationship dynamics for participants. Some relationships improved and brought people closer while also pushing others apart.

Pattern: Whether positively or negatively, each participant reported some social or relationship changes. It was most commonly seen, that those already close to a participant prior to their pain, became closer after their pain. While those that were distant friends prior to the pain, became more distant once the chronic pain set in.

Cluster 2: Chronic Pain Management

Question 1/2: Does anyone help you with your pain? How do they help?

When participants were asked this question, they often answered in two categories: being supported by family/partners/peers or being helped by physicians. Therefore, the salience and pattern for this question will be separated in the same manner.

Family/Partners/Peers

Salience: The help that participants claim to receive from their families, partners, and peers, tends to be that of support. This support can be either emotional or physical in nature and can be accomplished in close or far proximity to the participants. Some participants even reported crying or whining to their families as their first reaction to experiencing pain, prior to undergoing their other strategies. It was also seen that in some cases, that families and peers were used for information gathering about self-management strategies.

Pattern: Most participants receive emotional support from their families, partners, and/or peers. While they often provide information on self-management strategies, participants mainly go to them for their emotional support.

Physicians

Salience: These participants each had a myriad of doctors. While some described good experiences and interactions with easy referrals and manageable treatments, the vast majority reported negative experiences. Some participants report that the negative experiences are due to long referral waiting times, while others are constantly being dismissed by physicians, and solely being given medication that conflict with the participants' wishes.

Pattern: Though participants claim that their physicians help them, they seem to be displeased with the majority of their interactions. Some participants are constantly being dismissed and accused that their pain is in fact, not real, but psychosomatic, while others wait years to finally meet with a physician or specialist that will take the participant seriously and offer them a proper treatment plan.

Question 3: What do you do when you experience pain?

Salience: Pain relieving strategies differ amongst individuals as their pain is individualized. While some participants use heat packs, others prefer to use cold. However, most participants reported that they find some sort of distraction activity to be helpful. The goal of several participants is to try and relax and to find comfort through the pain. This is achieved through light self-massage, human contact, drinking tea, or meditation.

Pattern: While everyone's pain relief strategies are different, everyone mentioned taking some sort of medication. The medication varied between prescribed pain killers, over the counter medication to assist with pain relief, sleep aids, or muscle relaxants. Taking medication often accompanied the desire to isolate one's self, lay down and try to sleep it off, if possible.

Question 4: How did you discover those strategies?

Salience: Participants learned their myriad of strategies from many different sources. While some came from doctors or specialists, others came from the internet, YouTube, peers, family members, etc. For some participants, the strategies they use, that they find comforting were taught to them at a young age from their mothers.

Pattern: Trial and error is the most common manner in which participants have discovered their preferred pain relief strategies. As physicians often insist on patients reflecting on when their pain fluctuates, participants had a good idea of what activities and strategies occurred around these fluctuations. This provided participants with which strategies ease pain and which ones to avoid as they incur pain.

Question 5: What do you do if you experience pain in a public place?

Salience: Not all participants answered this question, however those that did, expressed that experiencing pain in public is difficult for them. Most participants stated that they try to push through the pain and continue what they are doing if they perceive it as important. However, they all revealed that they try to get home as soon as they can to where they all have pain relief strategies in place. Some participants also try to get home quickly to avoid added anxiety or judgement from onlookers.

Pattern: Each participant stated that when they experience pain in public, they try to get home as quickly as possible. Once home, they can 'shut down' and try to relax and undergo their pain relief strategies.

Cluster 3: Definitions

Question 1: What is Self-Management?

Salience: It is a necessary aspect in order to carry out all of the requirements of one's day. To some, this is referred to as being organized or using proper time management. To others, it is more specifically how to get through your day with whatever condition you might have.

Pattern: Participants refer to self-management as a way of getting by. It involves any and all actions and strategies needed to get through a day, typically with a condition.

Question 2: What is Self-Care?

Salience: Self-care involves activities that one does to prioritize themselves and their physical, mental and emotional health. While most participants stated that this term referred to self-love, one participant referred to it as knowing one's own limits.

Pattern: Participants referred to self-care as a luxury and self-indulgence in the realm of health. They describe it as for relaxation, beauty and pampering. It involves eating right, exercise, taking baths, getting manicures, resting, etc.

Question 3: What is Coping?

Salience: Coping was described by participants as mental or physical manners of dealing with their pain, whether they are actions or avoidant behaviours.

Pattern: Participants describe coping as the manner in which they react to their chronic pain in order to get through it.

Question 4: What is Self-Help?

Salience: There were many differing opinions on what self-help is. One participant referred to it as flaky nonsense from the 90s, whereas others referred to it as knowing one's self well enough to seek outward assistance and resources when needed.

Pattern: The most commonly stated view of self-help from participants was that when an individual cannot continue by themselves, they are aware enough to seek external support.

Question 5: What is Patient-Driven Health Care?

Salience: The participants described patient-driven health care, for the most part, as care opposite to what they have received. They describe it as an environment in which they are in control of their care and physicians take their concerns and desires into account.

Pattern: While patients often want a 'quick fix', participants described patient driven-health care to be a collaborative form of care. It places much of the onus on the patients and encourages them to be well informed when they speak to their physicians. In this manner, patients and doctors should be on the same page, when decisions are made regarding the patient's care.

Section 4 – Themes

These themes were derived from both saliences and patterns from within interviews, as well as cross comparisons by questions. The themes that emerged from the data are: Doctors, Getting Through the Day, Being Limited, My Hidden Burden, and What's Next.

Doctors

Throughout every interview, participants felt it important to discuss their experiences with their health care providers. Physicians play a crucial role when it comes to chronic pain, however most participants reported negative experiences with them. For those without a definitive diagnosis, a typical appointment involves the patient talking about their pain and how it affects them, the doctor then sending them for some tests, returning to tell them that nothing is wrong, and dismissing them. When the patient is dismissed, they are either told that their pain is psychosomatic, or they are issued pain medication. When a patient is dismissed with a psychological diagnosis, they enter a psychological paradox. They can either doubt their own pain and accept the diagnosis of their physician that it is purely psychological, or they can doubt their 'expert' physicians and live on with undiagnosed and unacknowledged pain for the rest of their lives. Providing the patient takes the medication, they must live with the numerous side effects and damage that the medication causes to the rest of their bodies. In either case, patients left their physicians offices, not feeling heard. Nancy explains this aspect perfectly when she said:

Well he just, I kept saying 'I have this pain down my leg, you know' and

I would show him the back of my leg, and he would say um, 'Oh it's

probably just growing pain, you're growing, it's growing pains.' He said it was from growing, 'cause I was really tall, I grew a lot in one year. I mean I've been almost this tall since grade six. Um, and for sure growing did exacerbate the, the birth defect that I have. Growing quickly, being tall, exacerbates that stuff but um, he just wouldn't, didn't, he didn't, my mom took me a couple times and he didn't, wasn't listening to me or to her, um, and that was it. [...] He just said, 'It's growing pains, happens to everyone, no big deal, don't worry about it'. He treated us like we were, in retrospect, like, just like we were hysterical women, kinda thing. Um, he didn't take us seriously at all. - Nancy

Unfortunately, Nancy was not alone in her negative interactions with physicians, as Olive also had to fight to be believed about her pain. She described her doctor patient interactions when she said:

I've been to a lot of doctors about it and its like, I've taken so much x-rays and medications and still nothing has solved it... and usually for like pain, they're like 'do this' and if you do it, it works right, but like if they're taking x-rays and they're not seeing anything like wrong with... you know what I mean, wrong with me. Um, and there's, like everything is intact, everything's great, and it sort of like makes you, the person who has the pain, question if you're really actually feeling the pain or if like you're just trying to inflict the pain by yourself in your head. And its like 'No, I, I know I'm feeling this pain! You just have to believe me

when I tell you that I'm feeling this pain! Um and I know that even if you're not seeing anything wrong there has to be something wrong somewhere.' You know what I mean, because like clearly, I'm, I'm still feeling the pain, so like, I think that's more of like how its affected me, is me thinking if this pain is real or not, and I think for a, like a, I had a time when I wasn't like, I wasn't so much as a, I was like 'You know what? Maybe we should be positive, and the pain will just go' you know? Since like they're telling me nothings wrong and its all in my head and I had a point where I was just kinda like 'kay 'no, the pain's not there'. It would be killing me but I'm just like 'no it's in my head, you just gotta think happy thoughts' and it's like, I mean, I know that like something is wrong so like we either gotta figure out what is wrong, or like I'm just gonna have to stay this way for the rest of my life. -Olive

In cases where there is a diagnosis, or physicians that believe a patient's pain to be real, there are some positive experiences, however there are also many negative interactions as well. Many participants expressed their frustrations at the process of finally getting the opportunity to see a specialist. To accomplish this, they had to justify their pain until a doctor believed them. Only then were they given medication and passed off the next doctor, where they were forced to wait extended amounts of time, in order to see the proper specialist. Many participants explained this phenomenon when they said:

Unfortunately, the only way he can help me is with medication. That has helped a lot, and I'm on some medication that I never thought I would be on, like I'm in time-released opiates now. [...] I have been

taken seriously by doctors for the most part, so I've been lucky and that's because I have something that's very physical on an X-Ray. I know that, you know if it wasn't physical, they wouldn't take it seriously. -Nancy

Similarly to Nancy, Sofia also has a visible source to her pain, unfortunately that does not always come with good physician experiences. Sofia described her frustration with referrals to specialists when she said:

I think in a perfect world it would be not having to go to your GP to get a referral to the particular specialist that you know you need, because I think that wastes everybody's time, and the having to justify yourself to this person to even get access to that person is problematic. -Sofia

In addition to the difficulty of being believed and proving that one's pain is real, Sarah also describes the difficulties of finding a specialist and of pain medications and their side effects. She said it best when she said:

I see multiple doctors, um, I have a pain clinic that I go to, um, so that's every few weeks. That took just six months to get even to see anyone. [...] I've tried so many medications and a lot of them have a lot of bad side effects, and like make me feel worse, or just like so tired, or like I, I'm just like I can't do anything on this, like I go off of it and tell my parents, I'm like this isn't the one or like you lose your appetite and it's just not good. Um, I see a neurologist in September. That appointment alone probably took a year to get, um, which is also really frustrating

in this situation because getting appointments take so long, and like, in the meanwhile I'm just like trial and error with medications. -Sarah

The difficulties of pain medications are not lost on other participants. Diana said it best when she was asked to describe how she managed her pain:

Sometimes I have to switch it up because like you, your body can get used to different meds, so I'll do ibuprofen, and if ibuprofen stops working, then you switch over to like naproxen and that'll stop working and you have to go back, its... my liver is just gonna die. -Diana

Getting Through the Day

A typical day for participants with chronic pain involved many plans, strategies, and different forms of care. While every participant had a different routine, with different medications, and different ways to get through their pain filled day, the manner in which they went about it was the same. The first step is to 'tough it out' and ignore the pain, in order to continue with your day as planned. Providing that does not work, the participants' next step is to isolate themselves and head home in any manner possible. Once home, the next step is to interact with the numerous strategies that participants already have in place to help them relax. If these fail, or are not sufficient, the participants will then try different methods of distraction in order to divert their thoughts from their pain. Providing that all of these strategies are insufficient, or at any point during this process, the participant may try and lay down in an effort to sleep through the pain. Diana describes trying to 'push through' the pain as much as she can, yet if that strategy fails, she describes trying to get home:

I try to massage, um, I do um, sometimes I'll just get into that mode where you're just like, I'm done, let me go home, and just like, kind of shut yourself down. Um, last year that happened a lot, but over the summer I tried to change that with myself and do more things [...] I try to push through that as much as I can, but sometimes it's just too much.

-Diana

For Laura, it's the anxiety accompanied by her pain that makes her long for safety. She describes this desperation to get to a safe place when she stated:

I usually just try to get home. Um, or I try to get to a spot that I can just like crash for two hours and kind of cope with it on my own. Like I'm a very private person, so just like experiencing pain in public, I feel like everyone is staring at me, like I feel like everyone knows and is like what is wrong with you. So, um, I try to isolate myself it's the only way I kind of deal with it. [...] Regardless, I always try to get back home and get back into my safe bed. -Laura

Nancy also emphasizes her preference to be in pain in her own space at home when she said:

I have that sort of pushing through it thing, which I would do for a [presentation] but otherwise I try to go home, if I can, and just work at home. I, I sort of, so I end up spending a lot of time at home, because then I can lay down and that's, it makes it a lot easier. I have cats too, I just watch my cats play, or I snuggle with my cats. When I'm out it's

really tough and, uh, and so I get a taxi and I go home if it gets really bad. -Nancy

Once participants arrived home, they described using medication or trying to sleep through the pain. Olive explained this when she said:

I just stick with more of like the medication that's been given to me. I've got a lot of like muscle relaxers and like um taking like ibuprofens and stuff like that and like, like serious medications for like pain, to help and so, it was, it's just basically what I do, or I just like lay in bed for a couple of hours. [...] It's more of just like home remedies, heating pads, medications and just like sleeping it off or like, sort of like relaxing, and watching a movie and stuff like that. It's not, at this point there's nothing really, I can do. -Olive

When medication isn't enough to ease some of the pain, participants began using their self-management strategies. Sarah explained some of hers when she said:

I usually go in my room, like I lay down. It's usually in the dark, um, I usually have an ice pack or something, um, I'll have water, like I don't have any screens, like I just try to just like, lay down, but sometimes it's worse when I lay down which sucks, 'cause you just want to like go in a dark room, and my head's just pounding and I can't really think about anything. Um, that can last a really long time, like if its really bad, and like, I try to just sleep it off, I'll probably like... so I take um, like sleep-aid stuff and I have muscle relaxants so, that kind of um, helps. But

yeah, um if it's like okay, I find um like, just going for a walk like around the neighbourhood. Like honestly it helps clear my head and sometimes just standing up, and like, fresh air can like, kind of help, and like, usually I'll go with someone so like just kind of like light conversation. Um, like a little bit of a distraction, like if I had something to focus on. Sometimes I'll watch something, like my friend will bring my laptop, like, Netflix, but usually like I try to just be unconscious, like I just want to sleep it off and then usually I'll feel a bit better. -Sarah

Failing all of the pre-determined self-management strategies, participants reported trying to distract themselves from their pain. Sofia explained this by saying:

So sometimes if nothing is working, I will try distraction, by getting my brain concentrating on something else. So, I'll be concentrating on various art things that I do like cross-stitch, knitting. Those to just, I'll go small motor instead of big motor. -Sofia

The strategies that participants use to manage their pain are all slightly different, yet the origin of discovery for these strategies are quite similar. The medication that participants take are typically recommended, and have their usage monitored by physicians. Some techniques for pain relief are often suggested by doctors as well. However, the vast majority of relaxation strategies stem from familial history. Participants reported that comforting behaviours such as heat packs, cups of tea, gentle massage, human contact, etc. were taught to them by their families, because 'That's just what we did' and it made them feel safe. These behaviours were often reinforced with trial and error and some outside research as well. For some, their strategies originated solely from specialists. Sarah describes her strategies when she said:

I see a physiatrist, so she's like kind of like a pain doctor, sports, um, and they taught me specific stretches. I went to, I go to physiotherapy too, and they told me similar stretches. -Sarah

When asked 'How did you discover that strategy?' many participants explained that experience over time and paying attention to the needs of their bodies helped.

I just discovered the walking because I worked all summer at a clothing retail store in the mall, not here, back home, and uh, I found that standing still it hurt more but when I started to walk around, it felt a hundred times better. Um, with the massaging, I learned it from my physiotherapist and the cream, I just always had the cream. -Diana

Nancy also describes this phenomenon when she said:

Years of experience [laughs]. I just pay attention to what works, and I think the therapy has really helped me to um, to figure out what works for me, so that's like a time when I can sort that stuff out you know. And I've had so many medical appointments and there's always all these questions, and um, over the years I can't even count how many medical appointments I've had, or X-rays or, I'm probably toxic. Um, so that's sort of helped me to figure it out, 'cause they're always asking 'What makes it better? What makes it worse?' that kind of thing, so I have to think about, it, it causes me to reflect, so I think that's where I found pretty much most of it, from experience. [...] most of the stuff that works is human contact or laying down, I've been doing that since I was 11.

Um, so that was just what my mom did, right. That's how I kinda learned that. -Nancy

When the advice of medical professionals was not sufficient for pain relief, Olive described using relaxation techniques she had developed for other aspects of her life.

The muscle relaxers one were like obviously you go to the hospital and they're like bam, bam, 'Here's medication. Why don't you take it, it will make you feel better for like 3 hours and then your pain will continue'. [laughing] Um, but I think the heating pad more, um the heating pad is kinda funny because it kind of goes with um, for like women having menstrual cycles. You sort of put a heating pad there. I'm just kinda like 'hey, why don't you put a heating pad on your back'. Like it's not the same thing but like heating pad helps. It keeps you warm and you feel all snuggly and great and maybe that makes the pain feel better, which it does right. Like it doesn't necessarily actually help with the pain, 'cause I don't think you're supposed to put hot stuff on stuff like that, but its supposed to be like cold pressed something, and it's like 'But I have heating pads so I'm just gonna use that'. -Olive

In addition to listening to their bodies over time, familial influence and familiarity played a factor in Laura's strategies as well. These are apparent when she said:

Researcher notes: She said most of the things she did were always 'just there'. She did things that were comfortable to her. She drinks tea and uses heat packs. She thinks that the heat helps. Her pain is worse in the

winter and she made a comment about her family being British so tea is in her blood. She said they didn't necessarily help the pain, but they helped comfort her. -Laura

Being Limited

Chronic pain had an effect on every participant regardless of the magnitude and severity. Whether this effect left the participant still standing, but in great discomfort or debilitated them, participants were all aware of the power their chronic pain held over them. For some participants, their mobility had become restricted, while for others, their pain controlled how long they were able to remain in certain positions such as standing or sitting. In either case, the physical limitations were readily visible, as were the social limitations. Several participants expressed cancelling or avoiding making plans, for fear that their limitations would prevent their attendance or enjoyment of the event. There are also emotional limitations, to avoid pity and judgement, which are less apparent. All of these limitations that chronic pain placed on these participants lead most of them to a state of longing. The desire is not only to 'be normal' or to return to their former way of life and pre-pain state, but also to try activities that are no longer available to them.

Chronic pain affects so many aspects of the participants' lives. Diana describes her pain affecting her life. She said:

Everyday with walking, writing, sitting, moving in general, sleeping... basically everything is affected. -Diana

These feelings are echoed by other participants as they also described how their pain has affected them. Nancy used an all-encompassing approach to her pain, she said:

It affects me tremendously, right, it affects my mood, it affects my mental health, it affects my relationships, it affects my work, family life, um, and it affects, also affects my mobility. -Nancy

The physical limitations associated with chronic pain are evident, however participants expressed that their pain also affected their desired activities. Sofia describes her limitations when she said:

It's very limiting with, for some of the things I have historically liked to do. [...] 'I guess I'll never be able to jump on a trampoline again'. Which is one of the, weirdly that's one of the things that I actually miss. I don't want to jump on a trampoline, I have not jumped on a trampoline since I was a teenager, but now I look at trampolines and that sky zone place or people that have trampolines in their backyards and I'm like [whines]. You know. [laughs] I don't want to drive, to go on a skidoo, or sea-doo or whatever those things are called. [...] I have friends that have both of those things. I've never had any interest on going on one, but now I bemoan the fact that I can't. -Sofia

In addition to the physical limitations, participants reported feeling socially and emotionally limited. Laura described how her pain controlled and limited her when she said:

Just like simple things, like going to the gym for more than 15-40 minutes, um, sitting down with friends and just eating a meal, and not having to cancel plans. Um, not having to travel with so many different

methods to kind of help manage the pain. You know like just being able to go over to someone's house and being like oh I didn't plan on sleeping over but yeah, I can, without thinking constantly like oh, I don't have this, I don't have this, I won't be able to sleep, ... um yeah those are some big, um for me. And like I know I'll probably never be able to travel. Like you see everyone going backpacking and being like that's not realistic for me when its tiresome to walk to the grocery store. Um, so yeah, its just a lot of readjusting, um, and talking down to experiences that I'm missing out on, like it probably wouldn't have been fun anyways. You know, things like that um, convincing myself that its not going to leave any kind of emotional damage or making me feel less than. Yeah but there's so many things that I would want to do that I see my friends doing. Um, it's not possible, anyways its just not a possibility for me. So, I kind of just have to accept that. -Laura

In addition to the many limitations set upon these participants by their chronic pain, there are moments where participants simply wished to be how they were prior to their pain. Sarah expresses her understanding that her pain is permanent, acknowledges all of the limitations it places upon her and also wishes that she could live a pain free life when she said:

This is my normal now so like I kind of have to adjust to it, and like, I mean like, it is a pain centered life. [...] Just not being able to study, like I would just have to lay in bed, honestly, just crying. I go to bed with like ice packs around my head. Um, and obviously mood, I feel like I'm not always, um, myself, and like obviously you get agitated, and like

people asking me things but like, I always tell, like, my close family and friends. Like they know so, like, they understand, like, if I just need to be alone or just like, they're really supportive. Um, even just like social life, going out, um, because it gets worse throughout the day, and just making plans in advance, I'm always like, I don't want to say yes, 'cause I'm like I'll see how I feel and like I want to of course. But, um, I'm like, I don't know, I can never really predict... unless if I start the day already waking up feeling awful, I know that like, it's just going to be a bad day. [...] I just wanna like feel normal, I wanna be how I was.

-Sarah

My Hidden Burden

People with chronic pain are given an inherent choice of whether or not to share the knowledge of their pain with others. Unfortunately, this scenario does not appear to have a 'right' answer. Participants explained that when they informed others of their pain, it resulted in either pity, or being accused of lying in order to seek attention. If the participant felt that they were being pitied or made to feel less than, they mostly chose to hide their pain and suffer with it alone in silence. Similarly, to how participants felt the need to justify the reality of their pain to their physicians, if participants were accused of attention seeking, then revealing their pain to peers required the same justification. Rather than adopting overly disabled behaviours to convince their peers of the legitimacy of their pain, they mostly chose to conceal their pain in an effort to avoid judgement. While both scenarios were likely to result in the privatization of one's pain, the burden did not solely fall on them. Those close to the participants used this as an

opportunity to relieve and share some of the physical and emotional burden, which strengthened their relationships. The opposite was also seen to be true, that distant peers of the participant took the participant's silence and change of mood and created more space between them.

Participants were not shy about describing their anxiety towards their chronic pain and others. Many described that their chronic pain put them on display for all of their peers to see and to be mocked for. Diana describes having to repeatedly defend the legitimacy of her pain to her judgemental peers:

I'd go to school, and I'd kinda be like this [tilts head to the right] and they'd be like 'oh you look a little crooked, but you're fine'. And like I could tell that I was like 'oh like it hurts a lot' and people were like [sarcastically] 'oh yeah'. Like, you know when you tell someone like 'oh I'm actually like not feeling well', and they're like 'oh yeah, uh huh, you're just trying to get out of...' whatever was happening that day. So, obviously, like you don't want to seem like you're faking, but like, it's painful. And like, I hide it... like I think it was like a month before I was... my mom was like 'okay, let's go get this checked out because clearly there's something wrong. -Diana

She continues on to explain that after she moved cities to avoid the prying eyes, she kept her pain private to avoid the pity she had become accustomed to:

Like the pity, like, I didn't want the pity. That's probably why I'm like more private about it, because I don't want to be like 'pity me and be

my friend', like. So, I know who's my friend because of me not because of what happened. -Diana

Many participants chose to only share their chronic pain with a select few family members and friends in order to avoid pity. However, as well intentioned and helpful as these people may be, they do not fully understand the extent to which chronic pain plagues the participants. Sarah explained her frustrations when she said:

Um, and my friends are good, but it's hard like, I feel like I used to complain a lot about it and like I think um, my family would kind of get frustrated, 'cause its like, they don't really know what to do, there's nothing you can like really do. Um, which is fine, like I would just like, not talk about it like, if every day is the same, I'm like, I kind of just don't mention it. Just, even if I don't say it, that doesn't mean that I'm not in pain, but I'm not going to like, tell everyone all the time, you know. It's like its kind of a given. -Sarah

When one's pain is not visible to everyone around them, participants reported feeling judged for claiming they were in pain. Laura shares her experience of being judged for sharing her pain with her superiors:

You have to walk in and say, 'I'm sorry but this is what I have to face in my day-to-day life'. So sometimes you feel like they're pitying you or sometimes its like 'oh she's not as capable as we thought'. Um. A lot of people think of it as I'm faking because they don't see. Um they don't

see it. I just look like a regular 23-year-old. So, I find that's a big topic or experience that I relate my chronic pain to. -Laura

Nancy explains her struggle of having pain and being different throughout different stages of her life. The pity and judgement she experienced as a child has taught her to be more open about her pain. She also discusses how her pain has changed her relationships, some for better and others for worse:

It's not so much pain I guess, but um, having, being different. Being different, so, you end up in a place where no one understands what it's like but you, and you can't explain it to anyone else, and when you're a child, it's a lot harder because you don't have the language for it, you know. I have the language for it now, a bit more, um, so there's that and then the experience of having surgery as a kid, I mean I had one friend who visited me in the hospital, but I had another friend whose mother wouldn't let her go to the hospital, 'cause she was, she didn't think it was a good place for a child. So, that changed, that kinda thing changed my friendships. And then coming back to school after being away 3 months in grade 6, and then having a back brace when I came back, so you're marked as physically different, but also being away and having everyone talk, that changed my relationships. I think it changed my relationships with my siblings, because I, I went away, I was only away for two weeks, right, I was only in Toronto in the hospital for two weeks, but that surgery, and that experience of that fundamentally changed me. [...] I went through all the um, without anybody. Except

my best friend, who came everyday to the hospital. That changed our relationship in a positive way, we became closer. She was there everyday, she tried to wash my hair in the hospital bed [laughs] she got water everywhere. So that was a positive thing having her there. I think my relationship with my parents, you know, it was difficult back then, you know, it changed, fundamentally changed my relationship with my parents when I was a child because I saw them, that they were afraid. And that, took away my feeling of safety, so I'm still working through that, but now, it, being in this situation again, I have the opportunity to revisit some of that childhood trauma, I would call it, and um, to talk to my parents about it and that's been really good this time. So, my relationship's changing with them again in a positive way. it's not all bad. -Nancy

For some, being selective over who they tell about their pain has affected their relationships as well. Sofia discovered that through her chronic pain she was able to discover who her 'real' friends were, rather than situational peers:

Some it's made better, some it's made a lot worse. Um, the better ones have been the ones where people are supportive and kind and loving, good people. The ones where 'oh well you can't do that anymore, yeah sorry you can't play golf with us anymore, not going to see you anymore, bye.' You know, those things that hurts. It's like um, okay, I thought we had a real friendship, nope, we played golf together. -Sofia

What's Next

As chronic pain is a fluctuating and uncertain embodied state, it brings about feelings of fear in many participants. This fear affects participants on good days as well as bad. On good days it makes them wary that it won't last, and on bad days it makes them fear future declines. Chronic pain and the future, however, are not always viewed as bleak for participants. Many participants are able to find positives within their chronic pain lives. For some, they discovered that different opportunities arose for them out of their pain. The majority of participants found that their chronic pain allowed them to change their perspective and achieve a more positive outlook on life. Especially on bad days when it is very easy to lose one's self in the despair and fear associated with chronic pain, participants spoke about using those moments to adopt their positive outlooks on life. Laura describes her fear of future declines as well as her mechanisms for changing from a depressed state to one with a more positive outlook:

So now I'm um, just like half living life, if that makes sense, and constantly wondering ok, at what point will I not be able to go to the gym at all um and kind of preparing for those future changes, those declines. [Pause] Oh and I don't know if other people do this as well. Personally, I have looked at like disability blogs, whenever I'm really down, like 'oh I couldn't get to the gym today', well, I just read about their experiences and I'm like, its kind of like a reality check for me too. And I'm like 'yeah ok so you couldn't do that, but you also have more capabilities than some other people so be appreciative of it'. Um, cause otherwise I find I just sit there and like just feel like oh the world has done you so wrong, and if you do that, and I'm not saying I'm like using

people's experiences of stories, but I'm just like checking my privilege and constantly reminding myself that I'm resilient. -Laura

Even on 'good' days, Sarah describes constantly thinking about her pain and waiting for it to take a turn for the worse, that she cannot enjoy these days when they come. She explained this when she said:

I'm always just worried that like, it's going to get worse throughout the day, and that's kind of like, the fear, like I'm always like too comfortable, like, today's good but like I honestly just try to make the best of it. -Sarah

However, the opposite is also true, participants found positives to emerge out of their pain. Olive described the positive changes that pain brought to her life when she said:

So, I think if anything, the back pain has sort of been like a blessing in disguise as in terms of like its, it's sort of helped me explore other things about myself, other personalities, personality traits that I didn't know I had, have sort of emerged out of the pain. Not like out of the actual pain but like, out of having the experience of the pain. -Olive

While chronic pain is not normally viewed in a positive light, having chronic pain caused Diana to make a lifestyle change that changed her life for the better:

I wouldn't have branched out so much. So, because I wanted to get away from anyone that knew me with the neck issue. So, coming here, nobody knew, and it made me feel I guess safer in a way. So, that was

*kinda positive, and then coming here I also branched out with my
confidence and everything, so I think that helped as well. -Diana*

Chapter 5: Discussion

The purpose of this phenomenological study was to describe and understand the meanings persons in Ontario ascribe to their chronic pain self-management. In this chapter, the findings from Chapter 4 will be discussed as well as compared and contrasted with the current body of chronic pain and self-management literature. This chapter will be presented in order of the five themes developed in chapter four: Doctors, Getting Through the Day, Being Limited, My Hidden Burden, and What's Next, and then a comparison of self-management definitions from the participants to those in the literature. Finally, the chapter will end off with a conclusion, limitations of this study, and some future directions.

Theme 1: Doctors

Throughout this study participants discussed their experiences with both formal and informal care at length as they played a crucial role in their pain management plans. While not every experience with a health care professional was negatively described, each participant had something negative to say about them, their service or the system in general. Many participants reported not being taken seriously at all and being dismissed repeatedly by physicians. For those without noticeable biomedical markers, they recounted being given unwanted medication and/or being issued a diagnosis by default that their pain was psychosomatic. These findings are consistent with those of Campbell and Guy (2007), Larun and Malterud (2007), Morden and colleagues (2011), Osborn and Smith (1998), and Snelgrove and Liossi (2013). While all participants described being on medication, many of them reported changing medication or altering the prescribed dose to alleviate some of the side effects, similar to the findings of Coyne

and colleagues (2015). Participants also described having to justify and legitimize their pain to physicians constantly. One participant began to doubt if her pain was actually genuine or if it was ‘all in her head’, this reaction is paralleled in Wendell’s book, *The Rejected Body* (1996).

Scarry mentioned that describing one’s pain can be a daunting task (1985). The patient, while in pain, must somehow explain and convince the physician, who is not in pain, in a short period of time that their pain is real. Participants described their pain to their physicians to the best of their abilities and only some were able to convince the physicians enough to send them for some X-rays or further testing. Contrary to the findings of Snelgrove and Lioffi (2013), participants did not report adopting overly disabled behaviours in order to be taken seriously or to gain a diagnosis. While participants did not speak to this phenomenon in particular, they mentioned the repetitiveness and constant dismissive atmosphere they encountered each time they sought out professional care. Adopting these overly disabled behaviours also affects one’s identity and sense of self, by changing one’s personal integrity and self-esteem (Snelgrove & Lioffi, 2013). Perhaps the participants felt that regardless of what they said or did, that they would still be dismissed by their physicians, similar to the findings of Morden and colleagues (2014). Rather than risk further stigma and changes to their identity for the likelihood that their physicians would dismiss them once again, may have been the reason that participants in this study did not adopt these overly disabled behaviours. For those participants that were believed to have genuine pain from physicians, they reported frustratingly extended wait times for specialists, which also enforces Morden and colleagues’ findings of doctors being perceived as ‘busy experts’ (2014).

With the negative experiences from traditional formal health care, every participant described attending some form of alternative therapy, similarly to the results found by Campbell

and Guy (2007). While many participants attempted numerous alternative therapies, the majority of participants did not find them helpful enough to continue them. Participants did however, report viewing those professionals in a positive light, which also mirrors the same findings from Campbell and Guy (2007). Despite the negative feelings that some participants had towards the health care system, none of the participants reported those feelings affecting their decision of whether or not to consult a physician, unlike the results from Morden and colleagues (2014). This may be due to Ontario's Health Insurance Plan (OHIP), which provides free access to physicians and medical advice ("What OHIP covers | Ontario.ca," n.d.).

Theme 2: Getting Through the Day

When participants were asked 'What do you do when you experience pain?' they were able to discuss some of their implemented strategies, however as the discussions continued, each participant revealed supplemental strategies. These strategies arose out of necessity and had become essential parts of the participants' daily routines, that they were not able to speak to them immediately when questioned. This finding was similar to that of Morden and colleagues, where participants had normalized their behaviours to an extent that those strategies did not seem worth mentioning (2011). In this study, participants reported trying to ignore the pain and work through it for as long as they could bare it while in public. Morden explained that this behaviour is used to retain a sense of normalcy in one's life, and to maintain one's pre-established identity (2011). For our participants, this involved maintaining their social and professional identities.

The strategies that participants used to comfort and soothe their pain varied, however they were all adapted over time, with trial and error, personal experience, and the input of others.

Providing that these behaviours were insufficient in managing one's pain, participants often turned to distraction, as a psychological technique to manage their pain. This was proven effective by Bushnell and colleagues, who demonstrated that by mentally occupying one's self, individuals could lessen their levels of pain, as well as how they perceived it (2013). Ong and colleagues discovered a similar phenomenon, whereby, their participants would mentally distract themselves in order to participate in a painful activity that they enjoyed (2011).

Participants spoke of the cathartic release they felt when they spoke to someone about their pain. Charmaz wrote that telling the story of one's suffering can be an important step in narrative reconstruction and managing one's condition (1999). This process of sharing one's narrative of suffering opens them up to the risk of moral judgments from others, such as not being believed, or imposing a further burden (Charmaz, 1999). To mitigate this, some participants chose to tell their stories to a professional, while other participants accepted the risk and opened up to their families and friends. Participants also reported seeking out others in similar situations to their own via YouTube, blogs, groups, forums, etc. This allowed them to feel as though they weren't alone, and to potentially learn new approaches to managing their type of pain. Wendell discussed that when she read about how others in her situation acted, she was able to identify, accept and improve her process of coming to terms with her own chronic condition (1996).

Theme 3: Being Limited

The physical effects and limitations chronic pain imposes on people are individualized by the type of pain they have and the person's current lifestyle. As certain tasks become too difficult

for a participant to accomplish on their own, they must either alter their lifestyle to omit that task or ask for help from others. Participants expressed their reluctance in asking for help, especially of those closest to them for fear that they are becoming a burden, similarly to the findings of Kowal and colleagues (2012). This reluctance for assistance could also be dictated by societies imposed need for independence (Wendell, 1996). Participants also expressed having aspects of their lives controlled by their pain. Their future social plans were at the mercy of their pain. Many participants tried to 'fight' through their pain to maintain their pre-established routines and personas, however over time, participants gave into their pain and altered their personalities to match. Rather than maintain their former social and familial roles, of making plans like they would have prior to their pain; their pain now controls their social lives and dictates what they are able to do. These findings match those of Crowe and colleagues, that found participants adopting overly vigilant behaviours to accommodate the needs of their bodies and their pain (2010). Keeping the needs of their bodies and pain in mind, many participants either gave up activities that they used to enjoy, or the desire of ever being able to participate in them.

Theme 4: My Hidden Burden

For participants whose pain developed and became chronic over time, rather than due to an acute incident, they reported not seeking out health care right away, which was also found by Morden and colleagues (2014). Although, over time as the pain became worse or never ceased, they sought out care. Whether they received a diagnosis or not, over time those around the participant began acting differently. For those with a diagnosis, the reaction tended to be pity, while other participants were accused of seeking attention. These participants had to constantly explain and justify the legitimacy of their pain to those around them, in a similar manner to their

behaviour with their physicians. This phenomenon has already been well documented for numerous invisible illnesses and conditions (Asbring, 2001; Campbell & Guy, 2007; Larun & Malterud, 2007; Osborn & Smith, 1998; Snelgrove & Liossi, 2013). The same feelings of frustration and anger that are associated with not being believed by doctors, applies to not being believed by their community (Snelgrove & Liossi, 2013). The participants in this study reacted in the same manner. It was found that even when speaking to one's family, over time the participant would cease telling them about her pain, because it had not changed and there was nothing anyone could do. While participants did not shut themselves off entirely from society, they began keeping their pain more private and only accepting help from close friends or family members. Contrary to the literature from Kowal and colleagues, participants did not report significant perceived burden on their family members or added burden on close relationships (2012). This may be due to participants being in denial that they are in fact a burden upon their families, or they may not be aware that they are causing a strain upon their relationships. When asked if their relationships were affected by their pain, one participant described that she didn't think it was a problem that she constantly asked her daughter to go do the groceries. She then added that perhaps her daughter might not feel the same way. Perhaps interviewing the family members and those that assist the person with chronic pain can shed more light on this phenomenon.

Theme 5: What's Next

This theme involved both fear and acceptance of current and future limitations related to their chronic pain. This fear affected participants' desire for the future, due to the fluctuating and

uncertain nature of chronic pain. Campbell and Guy reported that their participants expressed their fear of the future as well, however they tied these future fears with ruminations of the past (2007). Participants in this study, suggested that in some cases, when their pain was intractable, they would focus on the positive aspects of their lives, rather than dwell on their pain. Asbring explains that the limited capabilities associated with chronic illness demand change (2001). In these moments, people were able to pause and re-evaluate their lives, to re-focus their attentions on what mattered most. In some cases, they found that participants adopted a new perspective that allowed them to appreciate certain activities more, even if their participation in them was altered or removed altogether (Asbring, 2001). Participants in this study, tried to focus on their positives, mainly their accomplishments, and that they were better off than others, in order to appreciate what they have. This perspective was utilized, rather than continuing to focus on their pain and the activities they missed out on. Similarly to Asbring, these moments of positivity were often spoken of in the same conversation as a participant's fear for their future declines (2001).

What is Self-Management?

The overall comparisons of definitions of self-management and the associated concepts, from participants to those within the literature were fairly similar. While there were many judgements and misconceptions throughout the interviews, some terms were well understood. Self-management was described similarly by most participants to the definition derived from the literature. Although some participants thought of this as how to manage all of the aspects of one's life rather than solely for health or a condition, the main point of emphasis from participants was that this was a necessity. Alternatively, they described self-care as meant for

persons that did not have chronic pain or any other condition. Self-care was referred to as a luxury and privilege that participants did not feel they were entitled to, rather than for everyone and for overall health quality. Coping was well described and understood by participants and the literature alike, with most definitions stemming from, and only varying slightly from that of Lazarus and Folkman's definition from 1984. Patient-driven health care was also well understood, with participants expressing their desire for this manner of care to be implemented further. Lastly, self-help appeared to be the least understood concept from both participants and the literature alike. While the concept of seeking out aid remained consistent across all definitions, the rest of the concept differed greatly. To some, self-help was referred to as the 'flaky' self-help books from the 1980s and 1990s, and to others it was referred to as being intuitive enough to seek out professional support. Contrary to these impressions, the literature describes self-help as seeking external resources with a basis in psychology and intended for improving one's health. The difference between the perception of self-help from both academics and patients needs to be addressed to bridge the gap in knowledge between these two populations.

Conclusion

Living with a crippling, invisible condition such as chronic pain, forces patients to self-manage their conditions. This study explored the patient perspective of self-managing their chronic pain, in which five themes emerged as well as the delineation of six concepts, which were translated into plain language. By furthering the understanding of how persons with chronic pain live with and manage their pain, as well as bridging the gap between physicians and patients

through a common language, resources can now be made to further assist patients in their self-management.

Limitations

Six participants were included in the analysis of this study, which is acceptable for a qualitative study, and was enough to reach saturation (Creswell, 2013). While it had some variety in the ages of participants, they were all female, all from St. Catharines, Ontario, and all available in the late summer/early fall of 2018. Based on this sample, it is understandable to infer that these results are more transferable to the female population rather than attributed to all genders. However, these findings are consistent with those in the literature of studies that included males as well as females.

As recruitment for this study was conducted via Twitter and posters around the Brock University Campus, the population of participants were typically younger and had more access to academic information regarding their pain than the average chronic pain patient. Only interviewing the typically younger and technologically savvy generation of participants based on the methods of recruitment must also be acknowledged as a limitation.

Future Directions

This research should be continued with both males and females from not only other areas in Ontario, but also to other provinces to assess if self-management for chronic pain changes within different provincial health plans and gender differences. It is unknown if the participants

within this study were mainly female due to the nature of women feeling more free to express their pain journeys outwardly than men, that men are societally encouraged to act stoically regarding pain, perhaps due to males not wanting to look ‘weak’ in front of the female researcher, etc. More research should be conducted regarding gender norms and chronic pain to advance this field.

The delineation of self-management and associated concepts should also be further analyzed to create gold standard definitions in plain language throughout various fields, such as nursing, rehabilitation sciences, disability studies, etc. as well as to improve the working understanding of terms such as self-help, that differed greatly between academics and patients alike. Physicians should also be consulted regarding these terms to continue the conversation of plain language from academics all the way through to patients as they are the intermediaries. This research can also inspire the creation of resources from health organizations, to further close the gap of understanding between physicians and patients. It may also be used in campaigns to target the stigma that undiagnosed chronic pain is psychological and encourage those with chronic pain to cease suffering alone, in silence. These resources can take the form of brochures or pamphlets that are given to persons seeking care for their chronic pain. They can include the plain language definitions created in this thesis to assist patients in deciphering the instructions given to them by their physicians. They can also feature some potential ideas for persons with chronic pain to try for their self-management, such as to ‘try relaxing behaviours that you learned from your parents or in childhood’ as an example, ‘try distracting yourself from your pain’, perhaps even ‘sometimes sleeping through the pain can help’, etc.

References

- Aamland, A., Werner, E. L., & Malterud, K. (2013). Sickness absence, marginality, and medically unexplained physical symptoms: a focus-group study of patients' experiences. *Scand J Prim Health Care*, 31. <https://doi.org/10.3109/02813432.2013.788274>
- Aboagye, E., Karlsson, M. L., Hagberg, J., & Jensen, I. (2015). Cost-effectiveness of early interventions for non-specific low back pain: a randomized controlled study investigating medical yoga, exercise therapy and self-care advice. *Journal of Rehabilitation Medicine*, 47(2), 167–173.
- Albert, N. M. (2008a). Promoting Self-care in Heart Failure. *The Journal of Cardiovascular Nursing*, 23(3), 277–284. <https://doi.org/10.1097/01.JCN.0000305095.27635.4f>
- Albert, N. M. (2008b). Promoting self-care in heart failure: state of clinical practice based on the perspectives of healthcare systems and providers. *Journal of Cardiovascular Nursing*, 23(3), 277–284.
- Alligood, M. R. (2014). *Nursing theorists and their work*. Retrieved from https://books.google.ca/books?hl=en&lr=&id=qbAKAQAAQBAJ&oi=fnd&pg=PP1&dq=Self+Care+%2B+Applied+Health+Science&ots=wTkBiOl9w_&sig=2IqvlwMepTe8ErpEH2IIDA-xIA4#v=onepage&q=self+care&f=false
- AlMarshedi, A., Wills, G. B., & Ranchhod, A. (2015). The Wheel of Sukr: A Framework for Gamifying Diabetes Self-Management in Saudi Arabia. *Procedia Computer Science*, 63, 475–480. <https://doi.org/10.1016/J.PROCS.2015.08.370>
- Alvarado, M. M., Kum, H.-C., Gonzalez Coronado, K., Foster, M. J., Ortega, P., & Lawley, M. A. (2017). Barriers to Remote Health Interventions for Type 2 Diabetes: A Systematic Review and Proposed Classification Scheme. *Journal of Medical Internet Research*, 19(2), e28. <https://doi.org/10.2196/jmir.6382>
- Arafah, A. M., Bouchard, V., & Mayo, N. E. (2017). Enrolling and keeping participants in multiple sclerosis self-management interventions: a systematic review and meta-analysis. *Clinical Rehabilitation*, 31(316), 809–823. <https://doi.org/10.1177/0269215516658338>
- Asbring, P. (2001). Chronic illness - a disruption in life: identity-transformation among women with chronic fatigue syndrome and fibromyalgia. *Journal of Advanced Nursing*, 34(3), 312–319. <https://doi.org/10.1046/j.1365-2648.2001.01767.x>
- Åsbring, P., & Närvänen, A.-L. (2004). Patient Power and Control: A Study of Women with Uncertain Illness Trajectories. *Qualitative Health Research*, 14(2), 226–240. <https://doi.org/10.1177/1049732303260682>
- Bachem, R., & Maercker, A. (2016). Self-help interventions for adjustment disorder problems: a randomized waiting-list controlled study in a sample of burglary victims. *Cognitive Behaviour Therapy*, 45(5), 397–413. <https://doi.org/10.1080/16506073.2016.1191083>
- Bal, M. I., Sattoe, J. N. T., Roelofs, P. D. D. M., Bal, R., van Staa, A., & Miedema, H. S. (2016). Exploring effectiveness and effective components of self-management interventions for

- young people with chronic physical conditions: A systematic review. *Patient Education and Counseling*, 99(8), 1293–1309. <https://doi.org/10.1016/j.pec.2016.02.012>
- Barbaranelli, C., Lee, C. S., Vellone, E., & Riegel, B. (2015). The Problem With Cronbach's Alpha. *Nursing Research*, 64(2), 140–145. <https://doi.org/10.1097/NNR.0000000000000079>
- Barlow, C., Cooke, D., Mulligan, K., Beck, E., & Newman, S. (2010). A Critical Review of Self-Management and Educational Interventions in Inflammatory Bowel Disease. *Gastroenterology Nursing*, 33(1), 11–18. <https://doi.org/10.1097/SGA.0b013e3181ca03cc>
- Barlow, J., Wright, C., Sheasby, J., Turner, A., & Hainsworth, J. (2002). Self-management approaches for people with chronic conditions: a review. *Patient Education and Counseling*, 48(2), 177–187. [https://doi.org/10.1016/S0738-3991\(02\)00032-0](https://doi.org/10.1016/S0738-3991(02)00032-0)
- Barth, J., Jacob, T., Daha, I., & Critchley, J. A. (2015). Psychosocial interventions for smoking cessation in patients with coronary heart disease. In J. Barth (Ed.), *Cochrane Database of Systematic Reviews*. Chichester, UK: John Wiley & Sons, Ltd. <https://doi.org/10.1002/14651858.CD006886.pub2>
- Bastiaenen, C. H. G., de Bie, R. A., Vlaeyen, J. W. S., Goossens, M. E. J. B., Leffers, P., Wolters, P. M. J. C., ... Essed, G. G. M. (2008). Long-term effectiveness and costs of a brief self-management intervention in women with pregnancy-related low back pain after delivery. *BMC Pregnancy and Childbirth*, 8, 19. <https://doi.org/10.1186/1471-2393-8-19>
- Baydemir, C., Özdamar, K., & Ünalır, A. (2013). Validity of the Turkish version of the European Heart Failure Self-Care Behavior Scale. *Anadolu Kardiyol Derg*, 13(6), 573e579.
- Bedson, J., Mottram, S., Thomas, E., & Peat, G. (2007). Knee pain and osteoarthritis in the general population: what influences patients to consult? *Family Practice*, 24(5), 443–453. <https://doi.org/10.1093/fampra/cmm036>
- Behnke, E. A., Carr, D., Evans, J. C., Huertas-Jourda, J., Kockelmans, J. J., McKenna, W., ... Seebohm, T. M. (2013). *Encyclopedia of phenomenology* (Vol. 18). Springer Science & Business Media.
- Berzins, K., Reilly, S., Abell, J., Hughes, J., & Challis, D. (2009). UK self-care support initiatives for older patients with long-term conditions: a review. *Chronic Illness*, 5(1), 56–72.
- Blankers, M., Koeter, M. W. J., & Schippers, G. M. (2011). Internet therapy versus internet self-help versus no treatment for problematic alcohol use: A randomized controlled trial. *Journal of Consulting and Clinical Psychology*, 79(3), 330.
- Blickem, C., Bower, P., Protheroe, J., Kennedy, A., Vassilev, I., Sanders, C., ... Rogers, A. (2011). The role of information in supporting self-care in vascular conditions: a conceptual and empirical review. *Health & Social Care in the Community*, 19(5), 449–459. <https://doi.org/10.1111/j.1365-2524.2010.00975.x>
- Bodenheimer, T., Lorig, K., Holman, H., & Grumbach, K. (2002). Patient Self-management of Chronic Disease in Primary Care. *JAMA*, 288(19), 2469. <https://doi.org/10.1001/jama.288.19.2469>

- Boger, E., Ellis, J., Latter, S., Foster, C., Kennedy, A., Jones, F., ... Demain, S. (2015). Self-Management and Self-Management Support Outcomes: A Systematic Review and Mixed Research Synthesis of Stakeholder Views. *PloS One*, 10(7), e0130990. <https://doi.org/10.1371/journal.pone.0130990>
- Bonder, B. R., & Dal Bello-Haas, V. (2008). *Functional performance in older adults*. FA Davis.
- Brady, T. J., Murphy, L., O, B. J., Beauchesne, D., Daniels, B., Greenberg, M., ... Meta, al A. (2013). A Meta-Analysis of Health Status, Health Behaviors, and Health Care Utilization Outcomes of the Chronic Disease Self-Management Program. *Prev Chronic Dis*, 1010. <https://doi.org/10.5888/pcd10.120112>
- Brief, D. J., Rubin, A., Keane, T. M., Enggasser, J. L., Roy, M., Helmuth, E., ... Rosenbloom, D. (2013). Web intervention for OEF/OIF veterans with problem drinking and PTSD symptoms: A randomized clinical trial. *Journal of Consulting and Clinical Psychology*, 81(5), 890–900. <https://doi.org/10.1037/a0033697>
- Burke, L. A., & Hutchins, H. M. (2007). Training transfer: An integrative literature review. *Human Resource Development Review*, 6(3), 263–296.
- Burns, J. W., Nielson, W. R., Jensen, M. P., Heapy, A., Czlapiński, R., & Kerns, R. D. (2015). Specific and general therapeutic mechanisms in cognitive behavioral treatment of chronic pain. *Journal of Consulting and Clinical Psychology*, 83(1), 1–11. <https://doi.org/10.1037/a0037208>
- Bushnell, M. C., Ceko, M., & Low, L. A. (2013). Cognitive and emotional control of pain and its disruption in chronic pain. *Nat Rev Neurosci*, 14(7), 502–511. Retrieved from <http://dx.doi.org/10.1038/nrn3516>
- Cabrero-García, J., & López-Pina, J. A. (2008). Aggregated measures of functional disability in a nationally representative sample of disabled people: analysis of dimensionality according to gender and severity of disability. *Quality of Life Research*, 17(3), 425–436.
- Cameron, J., Ski, C. F., & Thompson, D. R. (2012a). Screening for determinants of self-care in patients with chronic heart failure. *Heart, Lung and Circulation*, 21(12), 806–808.
- Cameron, J., Ski, C. F., & Thompson, D. R. (2012b). Screening for determinants of self-care in patients with chronic heart failure. <https://doi.org/10.1016/j.hlc.2012.07.050>
- Cameron, J., Worrall-Carter, L., Page, K., Riegel, B., Lo, S. K., & Stewart, S. (2010). Does cognitive impairment predict poor self-care in patients with heart failure? *European Journal of Heart Failure*, 12(5), 508–515. <https://doi.org/10.1093/eurjhf/hfq042>
- Cameron, J., Worrall-Carter, L., Page, K., Riegel, B., Lo, S. K., & Stewart, S. (2010). Does cognitive impairment predict poor self-care in patients with heart failure? *European Journal of Heart Failure*, 12(5), 508–515.
- Campbell, C., & Guy, A. (2007). 'Why Can't They Do Anything for a Simple Back Problem?'. *Journal of Health Psychology*, 12(4), 641–652. <https://doi.org/10.1177/1359105307078171>
- Carleton, R. N., Afifi, T. O., Turner, S., Taillieu, T., El-Gabalawy, R., Sareen, J., & Asmundson, G. J. G. (2017). Chronic pain among public safety personnel in Canada. *Canadian Journal*

of Pain, 1(1), 237–246. <https://doi.org/10.1080/24740527.2017.1410431>

- Castillo-Montoya, M. (2016). Preparing for Interview Research : The Interview Protocol Refinement Framework. *The Qualitative Report*, 21(5), 811–831. <https://doi.org/Retrieved> from: <http://nsuworks.nova.edu/cgi/viewcontent.cgi?article=2337&context=tqr>
- Charmaz, K. (1995). The Body, Identity, and Self: Adapting To Impairment, 36(4). Retrieved from http://resolver.scholarsportal.info/resolve/00380253/v36i0004/657_tbiasati.xml
- Charmaz, K. (1999). Stories of Suffering: Subjective Tales and Research Narratives. *Qualitative Health Research*, 9(3), 362–382. <https://doi.org/10.1177/104973239900900306>
- Chaveepojnkamjorn, W., Pichainarong, N., Schelp, F. P., & Mahaweerawat, U. (2009). A randomized controlled trial to improve the quality of life of type 2 diabetic patients using a self-help group program.
- Cheatle, M. D. (2011). Depression, Chronic Pain, and Suicide by Overdose: On the Edge. *Pain Medicine*, 12(suppl 2), S43–S48. <https://doi.org/10.1111/j.1526-4637.2011.01131.x>
- Cosby, J. L., Francis, N., & Butler, C. C. (2007). The role of evidence in the decline of antibiotic use for common respiratory infections in primary care. *The Lancet Infectious Diseases*, 7(11), 749–756. [https://doi.org/10.1016/S1473-3099\(07\)70263-3](https://doi.org/10.1016/S1473-3099(07)70263-3)
- Coyne, K. S., Margolis, M. K., Yeomans, K., King, F. R., Chavoshi, S., Payne, K. A., & LoCasale, R. J. (2015). Opioid-Induced Constipation Among Patients with Chronic Noncancer Pain in the United States, Canada, Germany, and the United Kingdom: Laxative Use, Response, and Symptom Burden Over Time. *Pain Medicine*, 16(8), 1551–1565. <https://doi.org/10.1111/pme.12724>
- Creswell, J. W. (2013). *Qualitative inquiry and research design: Choosing among five approaches* (3rd ed.). Sage publications.
- Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. Sage.
- Crowe, M., Whitehead, L., Gagan, M. J., Baxter, G. D., Pankhurst, A., & Valledor, V. (2010). Listening to the body and talking to myself – the impact of chronic lower back pain: A qualitative study. *International Journal of Nursing Studies*, 47(5), 586–592. <https://doi.org/10.1016/j.ijnurstu.2009.09.012>
- da Conceição, A. P., dos Santos, M. A., dos Santos, B., & da Cruz, D. de A. L. M. (2015). Self-care in heart failure patients. *Revista Latino-Americana de Enfermagem*, 23(4), 578–86. <https://doi.org/10.1590/0104-1169.0288.2591>
- Dahlberg, K. (2006). The essence of essences – the search for meaning structures in phenomenological analysis of lifeworld phenomena. *International Journal of Qualitative Studies on Health and Well-Being*, 1(1), 11–19. <https://doi.org/10.1080/17482620500478405>
- Donnelly, M. G., & Karsten, A. M. (2017). Effects of programmed teaching errors on acquisition and durability of self-care skills. *Journal of Applied Behavior Analysis*.

- Dwarswaard, J., Bakker, E. J. M., van Staa, A., & Boeije, H. R. (2016). Self-management support from the perspective of patients with a chronic condition: a thematic synthesis of qualitative studies. *Health Expectations*, 19(2), 194–208. <https://doi.org/10.1111/hex.12346>
- Effing, T., Monninkhof, E. E., van der Valk, P. P. D. L. P. M., Zielhuis, G. G., Walters, E. H., van der Palen, J. J., & Zwerink, M. (2007). Self-management education for patients with chronic obstructive pulmonary disease. In T. Effing (Ed.), *Cochrane Database of Systematic Reviews*. Chichester, UK: John Wiley & Sons, Ltd. <https://doi.org/10.1002/14651858.CD002990.pub2>
- Eghdam, A., Scholl, J., Bartfai, A., & Koch, S. (2012). Information and communication technology to support self-management of patients with mild acquired cognitive impairments: systematic review. *Journal of Medical Internet Research*, 14(6), e159. <https://doi.org/10.2196/jmir.2275>
- Eldredge, L. K. B., Markham, C. M., Ruiter, R. A. C., Kok, G., & Parcel, G. S. (2016). *Planning health promotion programs: an intervention mapping approach*. John Wiley & Sons.
- Ellis, J., Boger, E., Latter, S., Kennedy, A., Jones, F., Foster, C., & Demain, S. (2017). Conceptualisation of the “good” self-manager: A qualitative investigation of stakeholder views on the self-management of long-term health conditions. *Social Science & Medicine*, 176(Complete), 25–33. Retrieved from http://resolver.scholarsportal.info/resolve/02779536/v176icomplete/25_cotsaqtsohc.xml
- Ersser, S. J., Latter, S., Sibley, A., Satherley, P. A., & Welbourne, S. (2007). Psychological and educational interventions for atopic eczema in children. In S. J. Ersser (Ed.), *Cochrane Database of Systematic Reviews*. Chichester, UK: John Wiley & Sons, Ltd. <https://doi.org/10.1002/14651858.CD004054.pub2>
- Faithfull, S., Cockle-Hearne, J., & Khoo, V. (2011). Self-management after prostate cancer treatment: evaluating the feasibility of providing a cognitive and behavioural programme for lower urinary tract symptoms. *BJU International*, 107(5), 783–790. <https://doi.org/10.1111/j.1464-410X.2010.09588.x>
- Farmahini Farahani, M., Purfarzad, Z., Ghorbani, M., Ghamari Zare, Z., & Ghorbani, F. (2016). The impact of Multimedia Software Support on the Knowledge and Self-Care Behaviors of Patients with Type 2 Diabetes: a Randomized Clinical Trial. *Journal of Caring Sciences*, 5(2), 111–20. <https://doi.org/10.15171/jcs.2016.012>
- Faulkner, A., & Ryrie, I. (2009). Strategies for living and lifestyle options. *The Art and Science of Mental Health Nursing*, 283.
- Fields, H. L. (2011). The Doctor’s Dilemma: Opiate Analgesics and Chronic Pain. *Neuron*, 69(4), 591–594. <https://doi.org/10.1016/j.neuron.2011.02.001>
- Floderus, B., Göransson, S., Alexanderson, K., & Aronsson, G. (2005). Self-estimated life situation in patients on long-term sick leave. *Journal of Rehabilitation Medicine (Taylor & Francis Ltd)*, 37(5), 291–299. Retrieved from <http://10.0.4.56/16501970510034422>
- Foster, G., Taylor, S. J. C., Eldridge, S., Ramsay, J., & Griffiths, C. J. (2007). Self-management education programmes by lay leaders for people with chronic conditions. *The Cochrane*

Library.

- Gallant, M. P., Spitze, G. D., & Prohaska, T. R. (2007). Help or Hindrance? How Family and Friends Influence Chronic Illness Self-Management among Older Adults. *Research on Aging*, 29(5), 375–409. <https://doi.org/10.1177/0164027507303169>
- Gaskin, D. J., & Richard, P. (2012). *The Economic Costs of Pain in the United States*. *The Journal of Pain* (Vol. 13). <https://doi.org/10.1016/j.jpain.2012.03.009>
- Gilmour, H. (2015). Chronic pain, activity restriction and flourishing mental health. *Statistics Canada*, 26(1), 15–22. Retrieved from <http://search.proquest.com/docview/1674460465/fulltextPDF/CECED82FC9CE4F9APQ/1?accountid=9744>
- Giorgi, A. (2009). *The descriptive phenomenological method in psychology: A modified Husserlian approach*. Duquesne University Press.
- Giorgi, A. (2012). The Descriptive Phenomenological Psychological Method. *Journal of Phenomenological Psychology*, 43(1), 3–12. <https://doi.org/10.1163/156916212X632934>
- Graham, L., Wright, J., Walwyn, R., Russell, A. M., Bryant, L., Farrin, A., & House, A. (2016). Measurement of adherence in a randomised controlled trial of a complex intervention: supported self-management for adults with learning disability and type 2 diabetes. *BMC Medical Research Methodology*, 16(1), 132. <https://doi.org/10.1186/s12874-016-0236-x>
- Greenwell, K., Featherstone, D., & Hoare, D. J. (2015). The application of intervention coding methodology to describe the tinnitus e-programme, an internet-delivered self-help intervention for tinnitus. *American Journal of Audiology*, 24(3), 311–315.
- Greenwell, K., Sereda, M., Coulson, N., El Refaie, A., & Hoare, D. J. (2016). A systematic review of techniques and effects of self-help interventions for tinnitus: Application of taxonomies from health psychology. *International Journal of Audiology*, 55(sup3), S79–S89. <https://doi.org/10.3109/14992027.2015.1137363>
- Grijpma, J. W., Tielen, M., van Staa, A. L., Maasdam, L., van Gelder, T., Berger, S. P., ... Massey, E. K. (2016). Kidney transplant patients' attitudes towards self-management support: A Q-methodological study. *Patient Education and Counseling*, 99(5), 836–843. <https://doi.org/10.1016/j.pec.2015.11.018>
- Guilera, G. (2015). Disability in bipolar I disorder: The 36-item World Health Organization Disability Assessment Schedule 2.0. *Journal of Affective Disorders*, 174(Complete), 353–360. Retrieved from http://resolver.scholarsportal.info/resolve/01650327/v174icomplete/353_dibidthodas2.xml
- Harman, K., Keating, E., Mayes, S., Walsh, J., & MacCallum, S. (2014). Insomnia in clients with chronic, work-related musculoskeletal pain in a work recovery rehabilitation program. *Work*, 48(2), 185–192. <https://doi.org/10.3233/WOR-131655>
- Hay, P., Bacaltchuk, J., Stefano, S., & Kashyap, P. (2009). Psychological treatments for bulimia nervosa and bingeing. *Cochrane Database Syst Rev*, 4(4).
- Hay, P. P., Bacaltchuk, J., Stefano, S., & Kashyap, P. (2009). Psychological treatments for

- bulimia nervosa and bingeing. In P. P. Hay (Ed.), *Cochrane Database of Systematic Reviews*. Chichester, UK: John Wiley & Sons, Ltd.
<https://doi.org/10.1002/14651858.CD000562.pub3>
- Herbst, N., Voderholzer, U., Stelzer, N., Knaevelsrud, C., Hertenstein, E., Schlegl, S., ... Külz, A. K. (2012). The potential of telemental health applications for obsessive–compulsive disorder. *Clinical Psychology Review*, 32(6), 454–466.
- Høy, B., Wagner, L., & Hall, E. O. C. (2007). Self-care as a health resource of elders: an integrative review of the concept. *Scandinavian Journal of Caring Sciences*, 21(4), 456–466.
- Hudson, J. L., Bundy, C., Coventry, P. A., & Dickens, C. (2014). Exploring the relationship between cognitive illness representations and poor emotional health and their combined association with diabetes self-care. A systematic review with meta-analysis. *Journal of Psychosomatic Research*, 76(4), 265–274.
- Hudson, J. L., Bundy, C., Coventry, P., Dickens, C., Wood, A., & Reeves, D. (2016). What are the combined effects of negative emotions and illness cognitions on self-care in people with type 2 diabetes? A longitudinal structural equation model. *Psychology & Health*, 31(7), 873–890. <https://doi.org/10.1080/08870446.2016.1156113>
- Hutting, N., Richardson, J., & Johnston, V. (2016). The role of self-management in the treatment of musculoskeletal disorders. *Manual Therapy*, 25, e15–e17.
- Hutting, N., Staal, J. B., Engels, J. A., Dettalle, S. I., Heerkens, Y. F., & Nijhuis-Van der Sanden, M. W. G. (2015). A self-management programme for employees with complaints of the arm, neck, or shoulder: short and middle term effects. *Physiotherapy*, 101, e620.
- Jackson, A. M., Gregory, S., & McKinstry, B. (2009). Self-help groups for patients with coronary heart disease as a resource for rehabilitation and secondary prevention—what is the evidence? *Heart & Lung: The Journal of Acute and Critical Care*, 38(3), 192–200.
- Jerez-Roig, J., Ferreira, L. M. de B. M., de Araújo, J. R. T., & Lima, K. C. (2017). Dynamics of activities of daily living performance in institutionalized older adults: A two-year longitudinal study. *Disability and Health Journal*, 10(2), 279–285.
- Jolly, K., Majothi, S., Sitch, A. J., Heneghan, N. R., Riley, R. D., Moore, D. J., ... Price, M. J. (2016). Self-management of health care behaviors for COPD: a systematic review and meta-analysis. *International Journal of Chronic Obstructive Pulmonary Disease*, 11, 305.
- Jones, F., McKevitt, C., Riazi, A., & Liston, M. (2017). How is rehabilitation with and without an integrated self-management approach perceived by UK community-dwelling stroke survivors? A qualitative process evaluation to explore implementation and contextual variations. *BMJ Open*, 7(4), e014109. <https://doi.org/10.1136/bmjopen-2016-014109>
- Jones, F., Riazi, A., & Norris, M. (2013). Self-management after stroke: time for some more questions? *Disability and Rehabilitation*, 35(3), 257–264.
<https://doi.org/10.3109/09638288.2012.691938>
- Kaldo, V., Ramnerö, J., & Jernelöv, S. (2015). Involving clients in treatment methods: A neglected interaction in the therapeutic relationship. *Journal of Consulting and Clinical*

Psychology, 83(6), 1136.

- Kanera, I. M., Willems, R. A., Bolman, C. A. W., Mesters, I., Zambon, V., Gijzen, B. C., & Lechner, L. (2016). Use and Appreciation of a Tailored Self-Management eHealth Intervention for Early Cancer Survivors: Process Evaluation of a Randomized Controlled Trial. *Journal of Medical Internet Research*, 18(8), e229. <https://doi.org/10.2196/jmir.5975>
- Kang, X., Dennison Himmelfarb, C. R., Li, Z., Zhang, J., Lv, R., & Guo, J. (2015). Construct Validity of the Chinese Version of the Self-care of Heart Failure Index Determined Using Structural Equation Modeling. *The Journal of Cardiovascular Nursing*, 30(3), 222–228. <https://doi.org/10.1097/JCN.0000000000000134>
- Kang, X., Himmelfarb, C. R. D., Li, Z., Zhang, J., Lv, R., & Guo, J. (2015). Construct validity of the Chinese version of the Self-care of Heart Failure Index determined using structural equation modeling. *Journal of Cardiovascular Nursing*, 30(3), 222–228.
- Kennedy, A., Bower, P., Reeves, D., Blakeman, T., Bowen, R., Chew-Graham, C., ... Rogers, A. (2013). Implementation of self management support for long term conditions in routine primary care settings: cluster randomised controlled trial. *BMJ*, 346. Retrieved from <http://www.bmj.com/content/346/bmj.f2882>
- Kenning, C., Coventry, P. A., Gibbons, C., Bee, P., Fisher, L., & Bower, P. (2015). Does patient experience of multimorbidity predict self-management and health outcomes in a prospective study in primary care? *Family Practice*, 32(3), 311–316. <https://doi.org/10.1093/fampra/cmz002>
- Ketelaar, S. M., Nieuwenhuijsen, K., Gärtner, F. R., Bolier, L., Smeets, O., & Sluiter, J. K. (2014). Mental Vitality @ Work: The effectiveness of a mental module for workers' health surveillance for nurses and allied health professionals, comparing two approaches in a cluster-randomised controlled trial. *International Archives of Occupational and Environmental Health*, 87(5), 527–538. <https://doi.org/10.1007/s00420-013-0893-6>
- Khan, N., Bower, P., & Rogers, A. (2007a). Guided self-help in primary care mental health. *The British Journal of Psychiatry*, 191(3). Retrieved from <http://bjp.rcpsych.org/content/191/3/206.full>
- Khan, N., Bower, P., & Rogers, A. (2007b). Guided self-help in primary care mental health. *The British Journal of Psychiatry*, 191(3). Retrieved from <http://bjp.rcpsych.org/content/191/3/206.full>
- Klippel, J. H., Stone, J. H., & White, P. H. (2008). *Primer on the rheumatic diseases*. Springer Science & Business Media.
- Köberich, S., Lohrmann, C., Mittag, O., & Dassen, T. (2015). Effects of a hospital-based education programme on self-care behaviour, care dependency and quality of life in patients with heart failure—a randomised controlled trial. *Journal of Clinical Nursing*, 24(11–12), 1643–1655.
- Korpershoek, Y., Bos-Touwen, I. D., de Man-van Ginkel, J. M., Lammers, J.-W., Schuurmans, M. J., & Trappenburg, J. (2016). Determinants of activation for self-management in patients with COPD. *International Journal of Chronic Obstructive Pulmonary Disease*, 11, 1757–

66. <https://doi.org/10.2147/COPD.S109016>

- Korstjens, I., May, A. M., van Weert, E., Mesters, I., Tan, F., Ros, W. J. G., ... van den Borne, B. (2008). Quality of Life After Self-Management Cancer Rehabilitation: A Randomized Controlled Trial Comparing Physical and Cognitive-Behavioral Training Versus Physical Training. *Psychosomatic Medicine*, 70(4), 422–429.
<https://doi.org/10.1097/PSY.0b013e31816e038f>
- Korstjens, I., May, A. M., Van Weert, E., Mesters, I., Tan, F., Ros, W. J. G., ... Van Der Schans, C. P. (n.d.). Quality of Life After Self-Management Cancer Rehabilitation: A Randomized Controlled Trial Comparing Physical and Cognitive-Behavioral Training Versus Physical Training. <https://doi.org/10.1097/PSY.0b013e31816e038f>
- Kowal, J., Wilson, K. G., McWilliams, L. A., Péloquin, K., & Duong, D. (2012). Self-perceived burden in chronic pain: Relevance, prevalence, and predictors. *PAIN®*, 153(8), 1735–1741.
<https://doi.org/10.1016/j.pain.2012.05.009>
- Kübler-Ross, E., Wessler, S., & Avioli, L. V. (1972). On Death and Dying. *JAMA: The Journal of the American Medical Association*, 221(2), 174.
<https://doi.org/10.1001/jama.1972.03200150040010>
- Larun, L., & Malterud, K. (2007). Identity and coping experiences in Chronic Fatigue Syndrome: A synthesis of qualitative studies. *Patient Education and Counseling*, 69(1), 20–28.
<https://doi.org/10.1016/j.pec.2007.06.008>
- Lau-Walker, M. (2009). Self-management in long-term health conditions—A complex concept poorly understood and applied? *Patient Education and Counseling*, 75(2). Retrieved from http://resolver.scholarsportal.info/resolve/07383991/v75i0002/290_silhcccpuaa.xml
- Laxy, M., Mielck, A., Hunger, M., Schunk, M., Meisinger, C., Rückert, I.-M., ... Holle, R. (2014). The association between patient-reported self-management behavior, intermediate clinical outcomes, and mortality in patients with type 2 diabetes: results from the KORA-A study. *Diabetes Care*, 37(6), 1604–12. <https://doi.org/10.2337/dc13-2533>
- Lazarus RS, Folkman S. Coping and adaptation. *Handbook of Behavioural Medicine*. 1984;282325.
- Lee, K., Johnson, M. H., Harris, J., & Sundram, F. (2016). The resource utilisation of medically unexplained physical symptoms. *SAGE Open Medicine*, 4, 205031211666621.
<https://doi.org/10.1177/2050312116666217>
- Lee, M.-C., Wu, S.-F. V., Hsieh, N.-C., & Tsai, J.-M. (2016). Self-Management Programs on eGFR, Depression, and Quality of Life among Patients with Chronic Kidney Disease: A Meta-Analysis. *Asian Nursing Research*, 10(4), 255–262.
<https://doi.org/10.1016/j.anr.2016.04.002>
- Lenferink, A., Brusse-Keizer, M., van der Valk, P. D., Frith, P. A., Zwerink, M., Monninkhof, E. M., ... Effing, T. W. (2017). Self-management interventions including action plans for exacerbations versus usual care in patients with chronic obstructive pulmonary disease. *The Cochrane Library*.
- Levy, M. A., Holttum, S., Dooley, J., & Ononaiye, M. (2016). Predictors of IAPT psychological

- well-being practitioners' intention to use CBT self-help materials routinely in their clinical practice. *The Cognitive Behaviour Therapist*, 9.
- Liddy, C., Johnston, S., Nash, K., Irving, H., & Davidson, R. (2016). Implementation and evolution of a regional chronic disease self-management program. *Can J Public Health*, 107(2), 194. <https://doi.org/10.17269/cjph.107.5126>
- Lim, S. H., Chan, S. W. C., & He, H.-G. (2015). Patients' Experiences of Performing Self-care of Stomas in the Initial Postoperative Period. *Cancer Nursing*, 38(3), 185–193. <https://doi.org/10.1097/NCC.0000000000000158>
- Lincoln, Y. S., & Denzin, N. K. (1998). *The landscape of qualitative research: Theories and issues*. Sage.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry* (Vol. 75). Sage.
- Lintvedt, O. K., Griffiths, K. M., Sørensen, K., Østvik, A. R., Wang, C. E. A., Eisemann, M., & Waterloo, K. (2013). Evaluating the effectiveness and efficacy of unguided internet-based self-help intervention for the prevention of depression: a randomized controlled trial. *Clinical Psychology & Psychotherapy*, 20(1), 10–27.
- Lu, Y., Xu, J., Zhao, W., & Han, H.-R. (2016). Measuring self-care in persons with type 2 diabetes: A systematic review. *Evaluation & the Health Professions*, 39(2), 131–184.
- Manzini, F. C., & Simonetti, J. P. (2009). NURSING CONSULTATION APPLIED TO HYPERTENSIVE CLIENTS: APPLICATION OF OREM'S SELF-CARE THEORY. *CONSULTA DE ENFERMERÍA APLICADA A CLIENTES PORTADORES DE HIPERTENSIÓN ARTERIAL: USO DE LA TEORÍA DEL AUTO CUIDADO DE OREM.*, 17(1), 113–119. Retrieved from <http://proxy.library.brocku.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=a9h&AN=37830431&site=ehost-live&scope=site>
- Martin, S., Chinnock, P., Perales, J., Lee, H., Lee, C. Y., Wu, Y., & Mavrodaris, A. (2010). Self-management interventions for people living with HIV/AIDS (Protocol) Self-management interventions for people living with HIV/AIDS (Protocol) i Self-management interventions for people living with HIV/AIDS (Protocol) Self-management interventions for. *Cochrane Database Syst Rev*, 10. Retrieved from <http://www.thecochranelibrary.com>
- Mawson, S., Nasr, N., Parker, J., Zheng, H., Davies, R., & Mountain, G. (2014a). Developing a personalised self-management system for post stroke rehabilitation; utilising a user-centred design methodology. *Disability and Rehabilitation: Assistive Technology*, 9(6), 521–528.
- Mawson, S., Nasr, N., Parker, J., Zheng, H., Davies, R., & Mountain, G. (2014b). Developing a personalised self-management system for post stroke rehabilitation; utilising a user-centred design methodology. *Disability and Rehabilitation: Assistive Technology*, 9(6), 521–528. <https://doi.org/10.3109/17483107.2013.840863>
- Mbuagbaw, L., Aronson, R., Walker, A., Brown, R. E., & Orzech, N. (2017). The LMC Skills, Confidence & Preparedness Index (SCPI): development and evaluation of a novel tool for assessing self-management in patients with diabetes. *Health and Quality of Life Outcomes*, 15(1), 27.

- McCracken, L. M., Gauntlett-Gilbert, J., & Vowles, K. E. (2007). The role of mindfulness in a contextual cognitive-behavioral analysis of chronic pain-related suffering and disability. *Pain, 131*(1), 63–69. <https://doi.org/10.1016/j.pain.2006.12.013>
- McCusker, J., Cole, M. G., Yaffe, M., Strumpf, E., Sewitch, M., Sussman, T., ... Belzile, E. (2016). A randomized trial of a depression self-care toolkit with or without lay telephone coaching for primary care patients with chronic physical conditions. *General Hospital Psychiatry, 48*(2), 101–107. <https://doi.org/10.1016/j.genhosppsych.2016.02.004>
- Milosavljevic, S., Clay, L., Bath, B., Trask, C., Penz, E., Stewart, S., ... McDonough, S. M. (2015). Walking away from back pain: one step at a time -- a community-based randomised controlled trial. *BMC Public Health, 15*(1), 144. <https://doi.org/10.1186/s12889-015-1496-9>
- Mittler, J. N., Martzolf, G. R., Telenko, S. J., & Scanlon, D. P. (2013). Making Sense of “Consumer Engagement” Initiatives to Improve Health and Health Care: A Conceptual Framework to Guide Policy and Practice. *The Milbank Quarterly, 91*(1), 37–77. <https://doi.org/10.1111/milq.12002>
- Morden, A., Jinks, C., & Bie Nio Ong, B. N. (2011). Lay models of self-management: how do people manage knee osteoarthritis in context? *Chronic Illness, 7*(3), 185–200. <https://doi.org/10.1177/1742395310391491>
- Morden, A., Jinks, C., & Ong, B. N. (2014). Understanding Help Seeking for Chronic Joint Pain. *Qualitative Health Research, 24*(7), 957–968. <https://doi.org/10.1177/1049732314539853>
- Moriyama, M., Nakano, M., Kuroe, Y., Nin, K., Niitani, M., & Nakaya, T. (2009). Efficacy of a self-management education program for people with type 2 diabetes: results of a 12 month trial. *Japan Journal of Nursing Science, 6*(1), 51–63.
- Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification Strategies for Establishing Reliability and Validity in Qualitative Research. *International Journal of Qualitative Methods, 1*(2), 13–22. <https://doi.org/10.1177/160940690200100202>
- Moulin, D. E., Clark, A. J., Speechley, M., & Morley-Forster, P. K. (2002). Chronic Pain in Canada - Prevalence, Treatment, Impact and the Role of Opioid Analgesia. *Pain Research and Management, 7*(4), 179–184. <https://doi.org/10.1155/2002/323085>
- Moustakas, C. (1994). *Phenomenological research methods*. Sage.
- Munce, S. E. P., Webster, F., Fehlings, M. G., Straus, S. E., Jang, E., & Jaglal, S. B. (2016). Meaning of self-management from the perspective of individuals with traumatic spinal cord injury, their caregivers, and acute care and rehabilitation managers: an opportunity for improved care delivery. *BMC Neurology, 16*(1), 11. <https://doi.org/10.1186/s12883-016-0534-2>
- Nolte, E., & McKee, M. (2008). *Caring for people with chronic conditions: a health system perspective*. McGraw-Hill Education (UK).
- Norman, I., & Ryrie, I. (2013). *The art and science of mental health nursing: Principles and practice: A textbook of principles and practice*. McGraw-Hill Education (UK).
- Norweg, A., & Collins, E. G. (2013). Evidence for cognitive-behavioral strategies improving

- dyspnea and related distress in COPD. *International Journal of Chronic Obstructive Pulmonary Disease*, 8, 439–51. <https://doi.org/10.2147/COPD.S30145>
- Ong, B. N., Jinks, C., & Morden, A. (2011). The hard work of self-management: Living with chronic knee pain. *International Journal of Qualitative Studies on Health and Well-Being*, 6(3), 7035. <https://doi.org/10.3402/qhw.v6i3.7035>
- Orem, D. E., Taylor, S. G., & Renpenning, K. M. (1995). Nursing: Concepts of practice.
- Ory, M. G., Ahn, S., Jiang, L., Lorig, K., Ritter, P., Laurent, D. D., ... Smith, M. L. (2013). National Study of Chronic Disease Self-Management. *Journal of Aging and Health*, 25(7), 1258–1274. <https://doi.org/10.1177/0898264313502531>
- Osborn, M., & Smith, J. A. (1998). The personal experience of chronic benign lower back pain: An interpretative phenomenological analysis. *British Journal of Health Psychology*, 3(1), 65–83. <https://doi.org/10.1111/j.2044-8287.1998.tb00556.x>
- Osborn, M., & Smith, J. A. (2006). Living with a body separate from the self. The experience of the body in chronic benign low back pain: an interpretative phenomenological analysis. *Scandinavian Journal of Caring Sciences*, 20(2), 216–222. <https://doi.org/10.1111/j.1471-6712.2006.00399.x>
- Ovayolu, O. U., Ovayolu, N., & Karadag, G. (2012). The relationship between self-care agency, disability levels and factors regarding these situations among patients with rheumatoid arthritis. *Journal of Clinical Nursing*, 21(1-2), 101–110.
- Oxford Dictionary. (n.d.-a). Chronic. Retrieved January 11, 2018, from <https://en.oxforddictionaries.com/definition/chronic>
- Oxford Dictionary. (n.d.-b). Psychogenic. Retrieved November 20, 2017, from <https://en.oxforddictionaries.com/definition/psychogenic>
- Pereira, T. T. S. O., & Santos, M. A. dos. (2012). Care group for mental health team: a professional development strategy. *Journal of Human Growth and Development*, 22(1), 68–72.
- Perry, J., Vandenkerkhof, E. G., Wilson, R., & Tripp, D. A. (2017). Guided Internet- based Psycho- educational Intervention Using Cognitive Behavioral Therapy and Self- management for Individuals with Chronic Pain: A Feasibility Study. *Pain Management Nursing*, 18(3), 179–189. <https://doi.org/10.1016/j.pmn.2016.12.003>
- Peters-Klimm, F., Freund, T., Kunz, C., Laux, G., Frankenstein, L., Müller-Tasch, T., & Szecsenyi, J. (2013). Determinants of heart failure self-care behaviour in community-based patients: a cross-sectional study. *European Journal of Cardiovascular Nursing*, 12(2), 167–176. <https://doi.org/10.1177/1474515112439964>
- Pinnock, H., Parke, H. L., Panagioti, M., Daines, L., Pearce, G., Epiphaniou, E., ... Taylor, S. J. C. (2017). Systematic meta-review of supported self-management for asthma: a healthcare perspective. *BMC Medicine*, 15(1), 64.
- Pratt, R., Halliday, E., & Maxwell, M. (2009). Professional and service-user perceptions of self-help in primary care mental health services. *Health & Social Care in the Community*, 17(2),

- Randall, S., & Neubeck, L. (2016). What's in a name? Concordance is better than adherence for promoting partnership and self-management of chronic disease. *Australian Journal of Primary Health*, 22(3), 181–184.
- Rash, C. J., & Petry, N. M. (2014). Psychological treatments for gambling disorder. *Psychology Research and Behavior Management*, 7, 285.
- Ratcliffe, G. E., Enns, M. W., Belik, S.-L., & Sareen, J. (2008). Chronic Pain Conditions and Suicidal Ideation and Suicide Attempts: An Epidemiologic Perspective. *The Clinical Journal of Pain*, 24(3), 204–210. <https://doi.org/10.1097/AJP.0b013e31815ca2a3>
- Reitsma, M. L., Tranmer, J. E., Buchanan, D. M., & VanDenKerkhof, E. G. (2012). The Epidemiology of Chronic Pain in Canadian Men and Women between 1994 and 2007: Results from the Longitudinal Component of the National Population Health Survey. *Pain Research and Management*, 17(3), 166–172. <https://doi.org/10.1155/2012/875924>
- Rhoades, K., Telliard, S., Thomas, T. S., & Barkin, J. L. (2016a). Applications of and barriers to holistic self-care in a low-income, high-risk obstetric population. *Women's Health Issues*, 26(6), 634–641.
- Rhoades, K., Telliard, S., Thomas, T. S., & Barkin, J. L. (2016b). Applications of and Barriers to Holistic Self-Care in a Low-Income, High-Risk Obstetric Population. *Women's Health Issues*, 26(6), 634–641. <https://doi.org/10.1016/j.whi.2016.08.004>
- Richard, A. A., & Shea, K. (2011a). Delineation of Self-Care and Associated Concepts. *Journal of Nursing Scholarship*, 43(3), no-no. <https://doi.org/10.1111/j.1547-5069.2011.01404.x>
- Richard, A. A., & Shea, K. (2011b). Delineation of self-care and associated concepts. *Journal of Nursing Scholarship*, 43(3), 255–264.
- Richards, D. (2004). Self-help: Empowering service users or aiding cash strapped mental health services? *Journal of Mental Health*, 13(2), 117–123. <https://doi.org/10.1080/09638230410001669246>
- Richardson, J., DePaul, V., Officer, A., Wilkins, S., Letts, L., Bosch, J., & Wishart, L. (2015). Development and Evaluation of Self-Management and Task-Oriented Approach to Rehabilitation Training (START) in the Home: Case Report. *Physical Therapy*, 95(6), 934–943. <https://doi.org/10.2522/ptj.20130617>
- Riekert, K. A., Ockene, J. K., & Pbert, L. (2013). *The handbook of health behavior change*. Springer Publishing Company.
- Robyn, P. J., Hill, A., Liu, Y., Souares, A., Savadogo, G., Sie, A., & Sauerborn, R. (2012). Econometric analysis to evaluate the effect of community-based health insurance on reducing informal self-care in Burkina Faso. *Health Policy and Planning*, 27(2), 156–165. <https://doi.org/10.1093/heapol/czr019>
- Robyn, P. J., Hill, A., Liu, Y., Souares, A., Savadogo, G., Sié, A., & Sauerborn, R. (2011). Econometric analysis to evaluate the effect of community-based health insurance on reducing informal self-care in Burkina Faso. *Health Policy and Planning*, 27(2), 156–165.

- Rodríguez-Gázquez, M. de los Á., Arredondo-Holguín, E., & Herrera-Cortés, R. (2012). Effectiveness of an educational program in nursing in the self-care of patients with heart failure: randomized controlled trial. *Efetividade de Um Programa Educativo Em Enfermagem No Autocuidado Em Pacientes Com Insuficiência Cardíaca: Ensaio Clínico Randomizado.*, 20(2), 296–306. Retrieved from <http://proxy.library.brocku.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=a9h&AN=77436587&site=ehost-live&scope=site>
- Ryan, A., Wilson, S., Taylor, A., & Greenfield, S. (2009). Factors associated with self-care activities among adults in the United Kingdom: a systematic review. *BMC Public Health*, 9, 96. <https://doi.org/10.1186/1471-2458-9-96>
- Sadler, E., Wolfe, C. D. A., Jones, F., & McKevitt, C. (2017). Exploring stroke survivors' and physiotherapists' views of self-management after stroke: a qualitative study in the UK. *BMJ Open*, 7(3), e011631. <https://doi.org/10.1136/bmjopen-2016-011631>
- Sanders, M. R. (2008). Triple P-Positive Parenting Program as a public health approach to strengthening parenting. *Journal of Family Psychology*, 22(4), 506.
- Satink, T., Josephsson, S., Zajec, J., Cup, E. H. C., de Swart, B. J. M., & Nijhuis-van der Sanden, M. W. G. (2016). Negotiating role management through everyday activities: narratives in action of two stroke survivors and their spouses. *Disability and Rehabilitation*, 38(24), 2354–2364. <https://doi.org/10.3109/09638288.2015.1129442>
- Sattoe, J. N. T. (2015). Self-management interventions for young people with chronic conditions: A systematic overview. *Patient Education and Counseling*, 98(6), 704–715. Retrieved from http://resolver.scholarsportal.info/resolve/07383991/v98i0006/704_sifypwccaso.xml
- Savage, E., Beirne, P. V, Ni Chroinin, M., Duff, A., Fitzgerald, T., & Farrell, D. (2011). Self-management education for cystic fibrosis. In E. Savage (Ed.), *Cochrane Database of Systematic Reviews*. Chichester, UK: John Wiley & Sons, Ltd. <https://doi.org/10.1002/14651858.CD007641.pub2>
- Scarry, E. (1985). *The body in pain: The making and unmaking of the world*. Oxford University Press, USA.
- Schneider, A., Rosenberger, S., Bobardt, J., Bungartz-Catak, J., Atmann, O., Haller, B., ... Enck, P. (2017). Self-help guidebook improved quality of life for patients with irritable bowel syndrome. *PLOS ONE*, 12(7), e0181764. <https://doi.org/10.1371/journal.pone.0181764>
- Schopflocher, D., Taenzer, P., & Jovey, R. (2011). The Prevalence of Chronic Pain in Canada. *Pain Research and Management*, 16(6), 445–450. <https://doi.org/10.1155/2011/876306>
- Schulman-Green, D., Jaser, S., Martin, F., Alonzo, A., Grey, M., McCorkle, R., ... Whittemore, R. (2012). Processes of Self-Management in Chronic Illness. *Journal of Nursing Scholarship*, 44(2), 136–144. <https://doi.org/10.1111/j.1547-5069.2012.01444.x>
- Schulman-Green, D., Jaser, S. S., Park, C., & Whittemore, R. (2016). A metasynthesis of factors affecting self-management of chronic illness. *Journal of Advanced Nursing*, 72(7), 1469–1489. <https://doi.org/10.1111/jan.12902>
- Shamji, M. F., Rodriguez, J., Shcharinsky, A., & Paul, D. (2016). High Rates of Undiagnosed

Psychological Distress Exist in a Referral Population for Spinal Cord Stimulation in the Management of Chronic Pain. *Neuromodulation: Technology at the Neural Interface*, 19(4), 414–421. <https://doi.org/10.1111/ner.12373>

Simmons, J. A., & Benson, B. E. (2013). *The new phenomenology: A philosophical introduction*. A&C Black.

Smith, B., & McGannon, K. R. (2018). Developing rigor in qualitative research: problems and opportunities within sport and exercise psychology. *International Review of Sport and Exercise Psychology*, 11(1), 101–121. <https://doi.org/10.1080/1750984X.2017.1317357>

Smith, S. M., Wallace, E., O'Dowd, T., & Fortin, M. (2016). Interventions for improving outcomes in patients with multimorbidity in primary care and community settings. *The Cochrane Library*.

Smith, S., Mitchell, C., & Bowler, S. (2007). Patient-Centered Education: Applying Learner-Centered Concepts to Asthma Education. *Journal of Asthma*, 44(10), 799–804. <https://doi.org/10.1080/02770900701645256>

Snelgrove, S., Edwards, S., & Liossi, C. (2013). A longitudinal study of patients' experiences of chronic low back pain using interpretative phenomenological analysis: changes and consistencies. *Psychology & Health*, 28(2), 121–138.

Snelgrove, S., & Liossi, C. (2013). Living with chronic low back pain: a metasynthesis of qualitative research. *Chronic Illness*, 9(4), 283–301. <https://doi.org/10.1177/1742395313476901>

Solberg, H. S., Steinsbekk, A., Solbjør, M., Granbo, R., & Garåsen, H. (2014). Characteristics of a self-management support programme applicable in primary health care: a qualitative study of users' and health professionals' perceptions. *BMC Health Services Research*, 14(1), 562. <https://doi.org/10.1186/s12913-014-0562-9>

Solomon, M., Wagner, S. L., & Goes, J. (2012). Effects of a Web-based intervention for adults with chronic conditions on patient activation: online randomized controlled trial. *Journal of Medical Internet Research*, 14(1), e32. <https://doi.org/10.2196/jmir.1924>

Song, M., Choi, S., Kim, S., Seo, K., & Lee, S. J. (2015). Intervention Mapping Protocol for Developing a Theory-Based Diabetes Self-Management Education Program. *Research and Theory for Nursing Practice*, 29(2), 94–112.

Spence Laschinger, H. K., Gilbert, S., Smith, L. M., & Leslie, K. (2010). Towards a comprehensive theory of nurse/patient empowerment: applying Kanter's empowerment theory to patient care. *Journal of Nursing Management*, 18(1), 4–13.

Spooner, L., Fernandes, K., Martins, D., Juurlink, D., Mamdani, M., Paterson, J. M., ... Gomes, T. (2016). High-Dose Opioid Prescribing and Opioid-Related Hospitalization: A Population-Based Study. *PLOS ONE*, 11(12), e0167479. <https://doi.org/10.1371/journal.pone.0167479>

Srinivas, P., Cornet, V., & Holden, R. (2017). Human factors analysis, design, and evaluation of Engage, a consumer health IT application for geriatric heart failure self-care. *International Journal of Human-Computer Interaction*, 33(4), 298–312.

- Strachan, P. H., Currie, K., Harkness, K., Spaling, M., & Clark, A. M. (2014). Context matters in heart failure self-care: a qualitative systematic review. *Journal of Cardiac Failure*, 20(6), 448–455.
- Sundslø, K., Espnes, G. A., & Söderhamn, O. (2013). Being old and living alone in urban areas: the meaning of self-care and health on the perception of life situation and identity. *Psychology Research and Behavior Management*, 6, 21. <https://doi.org/10.2147/PRBM.S46329>
- Talboom-Kamp, E. P., Verdijk, N. A., Kasteleyn, M. J., Harmans, L. M., Talboom, I. J., Looijmans-van den Akker, I., ... Chavannes, N. H. (2017). The Effect of Integration of Self-Management Web Platforms on Health Status in Chronic Obstructive Pulmonary Disease Management in Primary Care (e-Vita Study): Interrupted Time Series Design. *Journal of Medical Internet Research*, 19(8), e291. <https://doi.org/10.2196/jmir.8262>
- Thorsell, J., Finnes, A., Dahl, J., Lundgren, T., Gybrant, M., Gordh, T., & Buhrman, M. (2011). A comparative study of 2 manual-based self-help interventions, acceptance and commitment therapy and applied relaxation, for persons with chronic pain. *The Clinical Journal of Pain*, 27(8), 716–723.
- Turk, D. C. (2002). Clinical Effectiveness and Cost-Effectiveness of Treatments for Patients With Chronic Pain. *The Clinical Journal of Pain*, 18(6). Retrieved from http://journals.lww.com/clinicalpain/Fulltext/2002/11000/Clinical_Effectiveness_and_Cost_Effectiveness_of.3.aspx
- Vaccaro, J. A., & Huffman, F. G. (2012). Reducing health disparities: medical advice received for minorities with diabetes. *Journal of Health and Human Services Administration*, 389–417.
- Vagle, M. D. (2016). *Crafting phenomenological research*. Routledge.
- van den Berg, S. W., Peters, E. J., Kraaijeveld, J. F., Gielissen, M. F. M., & Prins, J. B. (2013). Usage of a generic web-based self-management intervention for breast cancer survivors: substudy analysis of the BREATH trial. *Journal of Medical Internet Research*, 15(8), e170. <https://doi.org/10.2196/jmir.2566>
- van der Heide, I., Uiters, E., Rademakers, J., Struijs, J. N., Schuit, A. J., & Baan, C. A. (2014). Associations Among Health Literacy, Diabetes Knowledge, and Self-Management Behavior in Adults with Diabetes: Results of a Dutch Cross-Sectional Study. *Journal of Health Communication*, 19(sup2), 115–131. <https://doi.org/10.1080/10810730.2014.936989>
- van Vugt, M., de Wit, M., Cleijne, W. H. J. J., & Snoek, F. J. (2013). Use of behavioral change techniques in web-based self-management programs for type 2 diabetes patients: systematic review. *Journal of Medical Internet Research*, 15(12), e279. <https://doi.org/10.2196/jmir.2800>
- Varley, R., Webb, T. L., & Sheeran, P. (2011). Making self-help more helpful: a randomized controlled trial of the impact of augmenting self-help materials with implementation intentions on promoting the effective self-management of anxiety symptoms. *Journal of Consulting and Clinical Psychology*, 79(1), 123.

- Vassilev, I., Rogers, A., Blickem, C., Brooks, H., Kapadia, D., Kennedy, A., ... Reeves, D. (2013). Social Networks, the “Work” and Work Force of Chronic Illness Self-Management: A Survey Analysis of Personal Communities. *PLoS ONE*, 8(4), e59723. <https://doi.org/10.1371/journal.pone.0059723>
- Vassilev, I., Rogers, A., Sanders, C., Kennedy, A., Blickem, C., Protheroe, J., ... Morris, R. (2011). Social networks, social capital and chronic illness self-management: a realist review. *Chronic Illness*, 7(1), 60–86. <https://doi.org/10.1177/1742395310383338>
- Vernooij, R. W. M., Willson, M., & Gagliardi, A. R. (2016). Characterizing patient-oriented tools that could be packaged with guidelines to promote self-management and guideline adoption: a meta-review. *Implementation Science*, 11(1), 52.
- Webster, F., Bremner, S., Oosenbrug, E., Durant, S., McCartney, C. J., & Katz, J. (2017). From Opiophobia to Overprescribing: A Critical Scoping Review of Medical Education Training for Chronic Pain. *Pain Medicine*, 15(4), 306. <https://doi.org/10.1093/pm/pnw352>
- Wendell, S. (1996). *The rejected body*. New York: Routledge.
- What OHIP covers | Ontario.ca [Internet]. [cited 2018 Dec 5]. Available from: <https://www.ontario.ca/page/what-ohip-covers>
- Wheelock, A., Miraldo, M., Thomson, A., Vincent, C., & Sevdalis, N. (2017). Evaluating the importance of policy amenable factors in explaining influenza vaccination: a cross-sectional multinational study. *BMJ Open*, 7(7), e014668.
- Wilson, F. L., Baker, L. M., Nordstrom, C. K., & Legwand, C. (2008). Using the Teach-Back and Orem’s Self-Care Deficit Nursing Theory to Increase Childhood Immunization Communication Among Low-Income Mothers. *Issues in Comprehensive Pediatric Nursing*, 31(1), 7–22. <https://doi.org/10.1080/01460860701877142>
- Wilson, M. G., Lavis, J. N., & Ellen, M. E. (2015). Supporting Chronic Pain Management across Provincial and Territorial Health Systems in Canada: Findings from Two Stakeholder Dialogues. *Pain Research and Management*, 20(5), 269–279. <https://doi.org/10.1155/2015/918976>
- Wilson, S., Chaloner, N., Osborn, M., & Gauntlett-Gilbert, J. (2017). Psychologically informed physiotherapy for chronic pain: patient experiences of treatment and therapeutic process. *Physiotherapy*, 103(1), 98–105. <https://doi.org/10.1016/j.physio.2015.11.005>
- Wilson, & Zandberg, L. J. (2012). Cognitive-behavioral guided self-help for eating disorders: Effectiveness and scalability. *Clinical Psychology Review*, 32(4), 343–357.
- Winkley, K., Stahl, D., Chamley, M., Stopford, R., Boughdady, M., Thomas, S., ... Ismail, K. (2016). Low attendance at structured education for people with newly diagnosed type 2 diabetes: General practice characteristics and individual patient factors predict uptake. *Patient Education and Counseling*, 99(1), 101–107. <https://doi.org/10.1016/j.pec.2015.08.015>
- Woolf, A. D., & Pfleger, B. (2003). Burden of major musculoskeletal conditions. *Bull World Health Organ*, 81.
- World Health Organization. (1983). Health education in self-care: Possibilities and limitations.

- Wu, S. V., Courtney, M., Edwards, H., McDowell, J., Shortridge-Baggett, L. M., & Chang, P. (2007). Self-efficacy, outcome expectations and self-care behaviour in people with type 2 diabetes in Taiwan. *Journal of Clinical Nursing*, 16(11c), 250–257.
- Zhang, K. M., Swartzman, L. C., Petrella, R. J., Gill, D. P., & Minda, J. P. (2017). Explaining the causal links between illness management and symptom reduction: Development of an evidence-based patient education strategy. *Patient Education and Counseling*, 100(6), 1169–1176. <https://doi.org/10.1016/j.pec.2017.01.009>
- Zhang, W., McLeod, C., & Koehoorn, M. (2016). The relationship between chronic conditions and absenteeism and associated costs in Canada. *Scandinavian Journal of Work, Environment & Health*, 42(5), 413–22. <https://doi.org/10.5271/sjweh.3583>
- Zheng, H., Nugent, C., McCullagh, P., Huang, Y., Zhang, S., Burns, W., ... Mawson, S. (2010). Smart self management: assistive technology to support people with chronic disease. *Journal of Telemedicine and Telecare*, 16(4), 224–227.
- Zrínyi, M., & Zékányiné, R. I. (2007). Does self-care agency change between hospital admission and discharge? An Orem-based investigation. *International Nursing Review*, 54(3), 256–262.
- Zwerink, M., Brusse-Keizer, M., van der Valk, P. D., Zielhuis, G. A., Monninkhof, E. M., van der Palen, J., ... Effing, T. (2014). Self management for patients with chronic obstructive pulmonary disease. In T. Effing (Ed.), *Cochrane Database of Systematic Reviews*. Chichester, UK: John Wiley & Sons, Ltd. <https://doi.org/10.1002/14651858.CD002990.pub3>

Appendix

Appendix A: Email or Telephone Communication Script Number One

Hi *(potential participant's name)*,

Thank you for expressing an interest in this research study.

My name is Rachel Richmond, and I am a Masters student in the Faculty of Applied Health Sciences at Brock University. I am currently conducting research under the supervision of Dr. Maureen Connolly on the self-management of chronic pain. This study involves a one-on-one interview at Brock University, lasting approximately an hour which we will schedule at your convenience. During the interview I will be asking you general questions regarding your pain, as well as how you manage it in your daily life. For example: "How does your chronic pain affect you?" Or "What do you do when you experience pain?"

Your involvement in this study is voluntary and you may choose not to answer a question or to leave at any time. The interview will be audio-recorded and safely stored to keep your information confidential.

If you still wish to participate, I must ask how long you have experienced your chronic pain to see if you qualify for this study.

Thank you for your time,

Rachel Richmond, MA Candidate
Faculty of Applied Health Science | Welsh Hall 145
Brock University

Appendix B: Letter of Invitation

Date: August/September 2018

Title of Study: A phenomenological Analysis of Chronic Pain Self-Management

Principal Student Investigator: Rachel Richmond, BKin, Graduate Student in the Department of Community Health at Brock University

Faculty Supervisor: Dr. Maureen Connolly, Associate Professor in the Faculty of Applied Health Sciences at Brock University

Brock University's Qualitative Research Lab would like to invite you to participate in a research project about chronic pain self-management. The purpose of this project is to give you the opportunity to share your experiences with pain.

I will be conducting one-on-one, in person interviews in an attempt to describe and understand the impact of chronic pain on one's daily life and the self-management behaviours of persons with chronic pain in Ontario.

The interview will last approximately one-hour, and will all take place individually in the Qualitative Research Lab at Brock University. The address is 1812 Sir Isaac Brock Way in St Catharines, ON, Canada.

Your participation will provide meaningful insight that will contribute to an improved understanding of how chronic pain affects people and how to improve self-management strategies for future sufferers.

Your participation in this study is strictly voluntary and you may refuse participation or withdraw at any time. Upon completing your interview, you will be compensated for any fees that were incurred due to your participation.

Please read the informed consent form for more information regarding the benefits and risks of participating, the methods that will be taken to ensure your confidentiality and the feedback you are entitled to as a participant. If you have any further questions regarding this study or your participation, please feel free to contact Dr. Connolly or myself at any time.

If you have any questions regarding your rights as a research participant, please contact a Brock University Research Ethics Officer at reb@brocku.ca or (905) 688-5550 ext. 3035.

Thank you,

Rachel Richmond
Graduate Student

Dr. Maureen Connolly
Associate Professor

(905) 688-5555 ext. 5903
Rm10sd@brocku.ca

(905) 688-5555 ext. 5340
mconnolly@brocku.ca

This study has been reviewed and received ethical clearance through Brock University's Research Ethics Board (*Insert REB file # here*).

Appendix C: Informed Consent Form

Date: August/September 2018

Project title: A phenomenological Analysis of Chronic Pain Self-Management

(REB file #:)

Principle Student Investigator

Rachel Richmond

Graduate Student

Faculty of Applied Health Sciences

(905) 688-5555 ext. 5903

rm10sd@brocku.ca

(Signature of Rachel Richmond)

Faculty Supervisor

Dr. Maureen Connolly

Associate Professor

Faculty of Applied Health Sciences

(905) 688-5555 ext. 3381

mconnolly@brocku.ca

(Signature of Maureen Connolly)

Invitation

Brock University's Qualitative Research Lab would like to invite you to participate in a research project about chronic pain self-management. The purpose of this project is to give you the opportunity to share your experiences with pain, which will be used to further understand how people with chronic pain manage their symptoms.

What is Involved

As a participant, you will be asked to complete a one-on-one interview with a researcher.

Interviews will be digitally audio-recorded and transcribed verbatim. Interviews will take place at Brock University, 1812 Sir Isaac Brock Way, St Catharines, ON, Canada, in the Qualitative Research Lab, located in Welsh Hall 145. Interviews will focus on your experiences with chronic pain and the ways in which you manage your pain. During the interview I will be asking you general open-ended questions regarding your pain, as well as how you manage it in your daily life. For example: "How does your chronic pain affect you?" Or "What do you do when you experience pain?" The interview will last approximately one-hour of your time in addition to administrative and travel time to and from the interview room. Only one interview is required. Near the end of the interview, I will present you with some definitions of self-management written by academics. Following this, I will ask you for your opinions on what they have written.

Potential Benefits and Risks

Possible benefits of participation include the opportunity to tell your chronic pain story, gain a deeper understanding of self-management and to understand your experiences in relation to other chronic pain participants. You will also be contributing to the understanding of the chronic pain self-management phenomenon in academic literature, which may in turn affect self-management prescription and education for persons with chronic pain. Along with participating in any research study there are inherent risks. For this study, reflecting upon instances of pain may result in increased stress or negative emotions. However, you have the right to avoid any question that makes you uncomfortable or that you would rather not discuss. Furthermore, the principal student investigator has formal training in qualitative interviewing and responding to chronic pain and is well prepared to manage such risks.

Confidentiality

Any information you provide will be kept confidential. Your name will not appear in this thesis nor any publications of these results; however, anonymous quotations may be used. The anonymity of participants will be ensured during both the process of the research as well as the dissemination of its results as it will be secured using encoded numbers and pseudonyms. All tangible data collected will be stored in a locked filing cabinet, in a locked room. Any digital data collected will be stored on a computer hard drive which will be username and password protected. Data will only be retained until the completion of this research project, at which time any hard copies will be shredded, and electronic files will be deleted and erased. This data will only be accessible by Rachel Richmond, the principle student investigator, and Dr. Maureen Connolly, the faculty supervisor. Should you have any questions regarding the security of your data or wish to see a copy of your transcript you may contact either Rachel Richmond or Dr. Maureen Connolly via telephone or e-mail. All requested transcripts will be delivered within twenty-four to forty-eight hours of the request. Upon completion of this research project, at the estimated date of 01/04/2019, all transcripts will be destroyed, and subsequently unavailable for request.

Voluntary Participation

Participation in this research is strictly voluntary. If you wish, you may decline to answer any questions throughout the interview. Furthermore, you may choose to withdraw your consent and participation at any point with no repercussions or loss of the benefits with which you are entitled. To withdraw from the study, you must contact the principal student investigator via telephone or email before the study has been completed and submitted for publication or for presentations at academic conferences. After the project has been submitted for publication, you may no longer be able to withdraw your confidential data from the study. The estimated time of completion and submission for publication is 01/04/2019. Should a participant choose to withdraw from the study, their audio file and transcribed word file will be deleted. Their hard copy version of their transcript will subsequently be shredded.

Publication of Results

Results of this study may be published in professional journals and presented at academic conferences. A one-page summary of the results will be emailed to all participants two weeks after the study has been completed. You are entitled to view a full-length copy of the thesis and you may request this at any time by contacting either the principal student investigator or the faculty supervisor via telephone or email. All documents will be issued within one week of the request.

Contact Information and Ethical Clearance

If you have any questions regarding this study or require any further information in order to make an informed decision, please contact the principal student investigator or the faculty supervisor using the provided contact information above. This study has been reviewed and accepted by Brock University's Research Ethics Board (*Insert REB file #*). If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca. Thank you for your interest and assistance in this project. Please keep a copy of this form for your records.

Consent Form

I agree to participate in the chronic pain self-management study described above. I have made this decision based on the information that I have read and understood in the Informed Consent Form. I have had the opportunity to receive any additional details I requested about the study, and I understand that I may continue to ask more questions in the future. I understand that I have the right to withdraw this consent and cease my participation at any time and that I have been given a copy of this form for my records.

Name of Participant: _____

Signature: _____

Date: _____

I have received \$20 from the interviewer.

Signature: _____

Appendix D: Map of Brock University

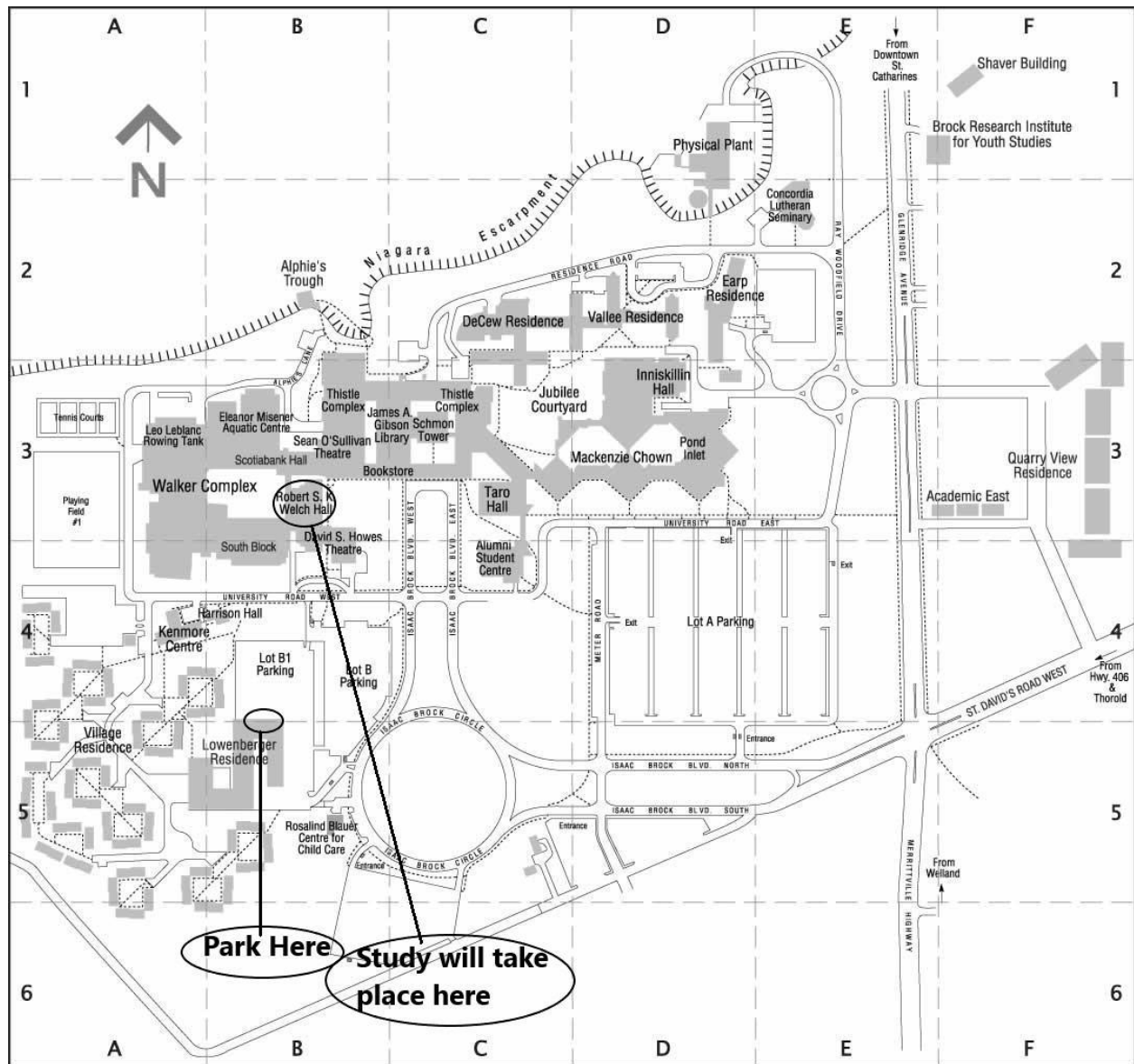


Figure 2. Map of Brock University

Appendix E: Confirmation Email

Hi *(potential participant's name)*,

Thank you for your continued interest in this research study. This letter is to remind you of your interview on chronic pain self-management on *(Time and Date of the Interview)*.

The interview will take place at Brock University in the Qualitative Research Laboratory located in Welsh Hall 145.

Parking will be provided in visitor parking near Lowenberger residence as indicated on your map. When you arrive on campus I will be waiting to escort you from your car to the interview room.

Brock University is located at 1812 Sir Isaac Brock Way, St Catharines, ON. You may use this information to find exact directions to the campus through www.google.ca/maps.

You are asked to be on campus fifteen minutes before your interview time. If at any point you get lost, are running late or cannot find parking, please call me at (905) 688-5555 ext. 5903. I would like to take this opportunity to ensure that you have read and understood the informed consent letter I sent you and that you have had the opportunity to ask me any questions or for more information. I would also like to remind you that your participation in this study is voluntary and that you may choose to withdraw your participation at any time.

Lastly, I would like to thank you for your cooperation, and for volunteering your time.

I am looking forward to our interview,

Sincerely,

Rachel Richmond, MA Candidate
Faculty of Applied Health Science | Welsh Hall 145
Brock University

Appendix F: Interview Agenda and Guide

A Phenomenological Analysis of Chronic Pain Self-Management

Script prior to interview:

Hi there, thank you again for your interest in the interview portion of my project. As I have mentioned before, my study aims to understand how people with chronic pain manage their symptoms. Our interview today will last approximately an hour in which I will be asking questions regarding your pain as well as any and all ways that you manage your pain, but first let's go over the informed consent form I sent you.

Review the informed consent form.

I will be audio recording this interview on my laptop, as well as I will be writing down some notes, if at any point you would like me to stop the recording and end our interview please let me know. Before we begin the interview, do you have any questions for me?

Answer and discuss questions.

If any questions arise at any point during our interview, feel free to ask me at any time. I will be more than happy to answer your questions.

Documentation that the researcher will fill in prior to the interview

Time of Interview:

Date:

Place: Welsh Hall 145, Qualitative Research Laboratory

Interviewer: Rachel Richmond

Participant Pseudonym:

Interview

Q1: How long have you experienced chronic pain?

Q2: How does your chronic pain affect you?

Q2.1: Physically

Q2.2: Psychologically

Q2.3: Emotionally

Q3: Who, if anyone helps you with your pain?

Q4: What do you do when you experience pain?

-note if they mention an experience with a physician and what it was

Q4.1: How did you discover that strategy?

Q4.2: Were there any other strategies you tried that didn't work?

Q5: What do you think self-management is?

Q5.1: What do you think self-care is?

Q5.2: What do you think coping is?

Q5.3: What do you think Self-help is?

Q5.4: What do you think patient-driven health care is?

Q6: Has your pain changed you?

-note: personality, activities...

Q6.1: Has it changed your relationships?

Q7: Academics define them as:

Self-Help is using any resource that empowers, educates, reduces mental health challenges, and/or encourages someone to be healthier.

Self-Help Groups are small groups of people that share an experience or illness. They meet regularly, virtually or physically, to support each other, share their stories, and give each other

advice. These groups may also participate in healthy activities together outside of their meetings, such as exercising.

Self-Care is anything someone does to maintain or improve their physical, mental or emotional health, for example, mindfulness, taking a bath, or exercising.

Self-Management is someone's ability to handle the negative effects that come with living with a chronic condition. It usually means changing their lifestyle and making decisions based on their condition, so they can live a better life. This can mean carrying out activities of daily living, such as eating to survive, or in some cases, it may involve hiring someone from the community to help them with those activities such as bathing regularly.

Coping is how someone reacts to a stressful situation, and then how they handle it.

Patient-Driven Health Care is anything a person does or is willing to do to take control of and improve their health. This kind of care is customized for the individual, based on their personality, preferences, and history.

Q8: Is there anything else about self-management and chronic pain that you'd like to discuss?

Post interview script:

Thank you very much for your participation. Your experiences are a crucial part to understanding self-management for people with chronic pain. Here is \$20 compensation for your time. From this point forward, your interview recording will be typed out verbatim and analyzed. It will be stored in this locked portion of this filing cabinet in this locked room. The only people with the key are myself, and my supervisor. Do you have any questions for me at this point?

Answer and discuss any questions or concerns.

Should you think of any, you have my contact information, please do not hesitate to contact me with questions at any point or refer a friend to my study. If that is all, I can escort you to your car now.

Appendix G: Member Checking

Date: August/September 2018

Title of Study: A phenomenological Analysis of Chronic Pain Self-Management

Principal Student Investigator: Rachel Richmond, BKin, Graduate Student in the Department of Community Health at Brock University

Faculty Supervisor: Dr. Maureen Connolly, Associate Professor in the Faculty of Applied Health Sciences at Brock University

We appreciate your participation in our study and thank you for spending the time helping us with our research!

In this study you were asked to discuss your self-management behaviours regarding your chronic pain. Near the end of the interview you were presented with definitions written by academics of self-management and some similar terms, at which point you were asked your opinions of these definitions. The purpose of this study was to understand chronic pain self-management from the perspectives of both academics and sufferers.

Attached to this e-mail is the transcript from your interview. We ask that you read through it to confirm that it reflects your feelings, experiences and views about your chronic pain self-management. Should you have any questions or comments relating to the transcript, please e-mail either myself at rm10sd@brocku.ca or Dr. Maureen Connolly at mconnolly@brocku.ca.

All information you provided is considered completely confidential. Your name will not be included or in any other way associated, with the data collected in the study. Any data derived solely from your transcript will be associated with a pseudonym. Furthermore, because the interest of this study is in the overall underlying themes of chronic pain self-management, you will not be identified individually in any way in any written reports of this research. Tangible copies of your transcript will be stored in a locked filing cabinet in Welsh Hall 145, which only myself and Dr. Connolly have access to. Electronic data and audio recordings will be kept on a private computer which is username and password protected. All identifying information will be removed from the records prior to storage. Once the study achieves publication stage, all hard copies of your transcript will be shredded, and any electronic files will be deleted.

This study has been reviewed and received ethics clearance through the Brock University Research Ethics Board. If you have any questions regarding your rights as a research participant,

please contact a Brock University Research Ethics Officer at reb@brocku.ca or (905) 688-5550 ext. 3035.

We really appreciate your participation and hope that this has been a rewarding experience for you. Thank you again,

Rachel Richmond, MA Candidate

Faculty of Applied Health Science | Welsh Hall 145

Brock University

Appendix H: Giorgi's Method in Action

Giorgi's 5 Steps:

1. Read the transcript as a whole repeatedly.
2. Re-read the data and separate it into meaning units (MU).
3. Transfer these MU into expressions relevant to the appropriate field.
4. Write an essential structure of the experience.
5. Synthesize these structures into representative statements.

The following analysis is only demonstrating one example from one interview of how the researcher arrived at the final results presented in this thesis in reverse order.

5. Theme title: My Hidden Burden.

4. Cluster: Understanding the effects of chronic pain.

3. The participant was accused of faking her pain. Rather than continually justifying it or feeling pitied by others, she chose to keep her pain hidden.

2. Um, everyday with walking, writing, sitting, moving in general, sleeping... basically everything is affected.

Um, basically it [laughing] I'm a bookworm, closet case that just doesn't talk to anybody. Uh, definitely coming here and meeting my best friend Uche has brought me out of my shell a lot. Um, I don't have as many friends as I used to in high school because of the, my neck, because I'm just so self-conscious about it. Um, but, um, between meeting new people I have opened up more than I was.

Like, if I hadn't had the thing with my neck I don't think I would've come here.

I think I would've went to college closer to home, I wouldn't have branched out so much. So, because I wanted to get away from anyone that knew me with the neck issue. So, coming here, nobody knew, and it made me feel I guess safer in a way. So, that was kinda positive, and then coming here I also branched out with my confidence and everything, so I think that helped as well.

[Interviewer: So, does that mean that you keep your pain more private?]

Um, I try to but what I've noticed is that um, with, when someone pays attention to me like, like zeros in on me, I get like twitchy, and I notice that, like I can tell that, that it hurts. And it hurts more when someone pays attention to me, so, people will be like 'oh, what is wrong with her...' like 'what is she doing'. So, I try to keep private like, um, I think people here at Brock like

my friends, only two people know. So, and then of course like if I have to, like I don't exactly, like if I need help in class or something, I don't exactly tell them, the professor exactly what's wrong I just kinda be like, 'if you need to know more go see my disability counsellor. But, yeah, I keep it more private.

Uh, usually I, I probably stress about it for a second, and 'I'm like there are so many people around', because like first off anxiety is a huge issue for me, which actually comes with a lot of chronic pain, um, and then I try to massage, um, I do um, sometimes I'll just get into that mode where you're just like, I'm done, let me go home. And just like, kind of shut yourself down. And do more things instead of like, say I was going out to the club with my friends and like I end up in pain, um, I'll either be like 'alright I'm out, bye' and my friends are like 'oh, you always leave early', and I'm like well you don't understand'. So, I try to push through that as much as I can, but sometimes it's just too much.

I used to cancel plans A LOT. And it was like 'she's a flake'. And I really hate that, so I try not to do that as much. And especially if I don't tell people and I keep like the 'why' private then they're just like 'She doesn't have a reason, she's just a flake, she's lazy', you know.

I definitely try to make more plans even if I flake on those too, like I try to be more interactive with my friends, to like show them that, 'I do care, I'm trying'. Like I'm not... 'I'm interested in what's happening.

I probably talked to my mom. Um, what I remember most was that I ignored it and then I was like 'mom, you know, my neck is like really bothering me.' And she was like 'oh, you're fine, just put some heat on it, you'll be fine'. And I was like 'okay', but like it really hurt and like I'd go to school, and I'd kinda be like this [tilts head to the right] and they'd be like 'oh you look a little crooked, but you're fine'. And like I could tell that I was like 'oh like it hurts a lot' and people were like [sarcastically] 'oh yeah'. Like, you know when you tell someone like 'oh I'm actually like not feeling well', and they're like 'oh yeah, uh huh, you're just trying to get out of...' whatever was happening that day. So, obviously, like you don't want to seem like you're faking, but like, it's painful. And like, I hide it... like I think it was like a month before I was... my mom was like 'okay, let's go get this checked out because clearly there's something wrong and I was like finally like c'mon.

Um, I would say that I used to be more, I'd say more talkative, more outgoing, just more involved in everything. More out there, and I'm much more closed off and I guess shy now.

And I just felt for myself, that like everybody was, obviously, I don't think obviously they were, or I wouldn't know, but like would just judge me on like everyday no matter what. So, I just thought for myself that it would be better to move away from that and get a new fresh start where, when people looked at me I wouldn't be like 'oh they're thinking about me or my injury or my pain or thinking about how flaky I used to be or still am'. So, coming here was definitely better. Also like the pity, like, I didn't want the pity. That's probably why I'm like more private about it, because I don't want to be like 'pity me and be my friend', like [laughs]. So, I know who's my friend because of me not because of what happened.

1. By re-reading the interviews, the researcher was able to put herself back into the room with the participants and understand the interviews from a holistic perspective.

Appendix I

Table 2: Self-Management Characteristics

Illness Population	Manage Symptoms	Behaviour Change	Performed Individually	Psychological Consequences	Decision Making	Action/Task	Develop Skills	Physical Consequences
(Alvarado et al., 2017; Arafah, Bouchard, & Mayo, 2017; Barlow et al., 2010; Barlow et al., 2002; Bastiaenen et al., 2008; Boger et al., 2015; Dwarswaard, Bakker, van Staa, & Boeije, 2016; Effing et al., 2007; Eghdam, Scholl, Bartfai, & Koch,	(AlMarshedi, Wills, & Ranchhod, 2015; Arafah et al., 2017; Barlow et al., 2010; Barlow et al., 2002; Bastiaenen et al., 2008; Burns et al., 2015; Dwarswaard et al., 2016; Eghdam et al., 2012; Eldredge et al., 2016; Ellis, Boger, Latter, Kennedy,	(Albert, 2008b; Alvarado et al., 2017; Arafah et al., 2017; Barlow et al., 2010; Barlow et al., 2002; Bastiaenen et al., 2008; Boger et al., 2015; Burns et al., 2015; Dwarswaard et al., 2016; Eghdam et al., 2012; Effing et al., 2007; Eldredge et al., 2016; Graham et al., 2016;	(Albert, 2008a; Alvarado et al., 2017; Arafah et al., 2017; C. Barlow et al., 2010; J. Barlow et al., 2002; Bastiaenen et al., 2008; Boger et al., 2015; Brief et al., 2013; Dwarswaard et al., 2016; Eghdam et al., 2012; Ellis, J., Boger, E., Latter, S., Kennedy, A., Jones, F., Foster, C., & Demain,	(Arafah et al., 2017; C. Barlow et al., 2010; Bastiaenen et al., 2008; Boger et al., 2015; Dwarswaard et al., 2016; Eghdam et al., 2012; Hutting et al., 2015; Jones et al., 2017, 2013; Kenning et al., 2015; Korpershoek et al., 2016; M.-C. Lee et al., 2016; Lim et al., 2015; Martin et al., 2010; Munce et al., 2016; Nolte & McKee, 2008; Norman & Ryrie, 2013; Richard & Shea, 2011a; Richards, 2004; Riekert et al., 2013; Sadler	(C. Barlow et al., 2010; Boger et al., 2015; Hutting et al., 2015, 2016; Jones et al., 2013; Kanera et al., 2016; Korpershoek et al., 2016; Korstjens et al., 2008; Laxy et al., 2014; M.-C. Lee et al., 2016; Lenferink et al.,	(AlMarshedi et al., 2015; Alvarado et al., 2017; C. Barlow et al., 2010; Boger et al., 2015; Burke & Hutchins, 2007; Hutting et al., 2016; Jones et al., 2017; Kanera et al., 2016; Klippel et al., 2008; Korpershoek et al., 2016; Korstjens et al., 2008; Lau-Walker, 2009; Laxy et al., 2014; Martin et al., 2010; Nolte & McKee, 2008; Norman & Ryrie, 2013;	(Burke & Hutchins, 2007; Burns et al., 2015; Ellis, J., Boger, E., Latter, S., Kennedy, A., Jones, F., Foster, C., & Demain, 2017; Ersser, Latter, Sibley, Satherley, & Welbourne, 2007; Hutting et al., 2016; Jolly et al., 2016; Jones et al., 2013; Klippel et al., 2008; Korpershoek et al., 2016; Lau-Walker, 2009; Lenferink et al., 2017; Martin et al., 2010; Mbuagbaw et	(Arafah et al., 2017; J. Barlow et al., 2002; Bastiaenen et al., 2008; Dwarswaard et al., 2016; Eghdam et al., 2012; Hutting et al., 2015; Jones et al., 2013; Kenning et al., 2015; Korpershoek et al., 2016; M.-C. Lee et al., 2016; Martin et al., 2010; Munce et al., 2016; Nolte & McKee, 2008; Norman & Ryrie, 2013; Sadler et al., 2017; Satink et al., 2016; Sattoe, 2015; van Vugt et al., 2013)

2012; Eldredge, Markham, Ruiter, Kok, & Parcel, 2016; Ellis, Boger, Latter, Kennedy, Jones, Foster, & Demain, 2017; Foster et al., 2007; Graham et al., 2016; Grijpma et al., 2016; Hutting et al., 2015, 2016; Jones et al., 2013; Kenning et al., 2015; Klippel et al., 2008; Korpershoek et al., 2016; Lim et al., 2017, 2013; Klippel et al., 2008; Korpershoek et al., 2016; Korstjens et al., 2008; Lau-Walker, 2009; Lee, Johnson, Harris, & Sundram, 2016; Lee et al., 2016; Lim et al.,	Jones, Foster, & Demain, 2017; Graham et al., 2016; Grijpma et al., 2016; Hutting et al., 2015, 2016; Jolly et al., 2016; Jones et al., 2017, 2013; Klippel et al., 2008; Korpershoek et al., 2016; Korstjens et al., 2008; Lau-Walker, 2009; Lee, Johnson, Harris, & Sundram, 2016; Lee et al., 2016; Lim et al.,	Hutting et al., 2015; Jolly et al., 2016; Jones et al., 2013; Kanera et al., 2016; Korpershoek et al., 2016; Laxy et al., 2014; Lim et al., 2015; Martin et al., 2010; Munce et al., 2016; Norman & Ryrie, 2013; Norweg & Collins, 2013; Pinnock et al., 2017; Richard & Shea, 2011a; Richardso et al., 2015;	2017; Foster et al., 2007; Graham et al., 2016; Jones et al., 2013; Kennedy et al., 2013; Kenning et al., 2015; Klippel et al., 2008; Korpershoek et al., 2016; Laxy et al., 2014; M.-C. Lee et al., 2016; Lenferink et al., 2017; Martin et al., 2010; Mittler et al., 2013; Munce et al., 2016; Nolte & McKee, 2008; Norman & Ryrie, 2013; Randall &	et al., 2017; Satink et al., 2016; Schulman-Green et al., 2016; Talboom-Kamp et al., 2017; van Vugt et al., 2013)	2017; Martin et al., 2010; Mbuagba et al., 2017; Munce et al., 2016; Norman & Ryrie, 2013; Norweg & Collins, 2013; Pinnock et al., 2017; Richard & Shea, 2011a; Richards et al., 2015; Riekert et al., 2013; Sanders, 2008; S. Smith et al., 2007; Vaccaro &	Norweg & Collins, 2013; Riekert et al., 2013; Satink et al., 2016; Vaccaro & Huffman, 2012; van der Heide et al., 2014; van Vugt et al., 2013; Vernooij et al., 2016; Wheelock et al., 2017)	al., 2017; Moriyama et al., 2009; Norweg & Collins, 2013; Richard & Shea, 2011a; Sadler et al., 2017; Sanders, 2008; Solomon et al., 2012; Vernooij et al., 2016; Zwerink et al., 2014)	
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2016; Lau-Walker, 2009; Lee, Wu, Hsieh, & Tsai, 2016; Martin et al., 2010; Mbuagba w, Aronson, Walker, Brown, & Orzech, 2017; Mittler, Martsof, Telenko, & Scanlon, 2013; Moriyama et al., 2009; Munce et al., 2016; Nolte & McKee, 2008; Norman & Ryrie,	2015; Martin et al., 2010; Mbuagba w et al., 2017; Mittler et al., 2013; Munce et al., 2016; Nolte & McKee, 2008; Norman & Ryrie, 2013; Richard & Shea, 2011b; Sadler et al., 2017; Satink et al., 2016; Sattoe, 2015; Savage et al., 2011; Schulman-Green et al., 2016; Smith et al., 2016; Solomon	Riekert et al., 2013; Sadler et al., 2017; Satink et al., 2016; Sattoe, 2015; Schulman-Green et al., 2016; Smith et al., 2007; Solomon et al., 2012; Spence Lasching et al., 2010; Talboom-Kamp et al., 2017; Vaccaro & Huffman, 2012; Wheelock et al., 2017; Zhang, Swartzman, Petrella, Gill, &	Neubeck, 2016; Richard & Shea, 2011b; Richards, 2004; Sadler et al., 2017; Sattoe, 2015; Schulman-Green et al., 2016; Vaccaro & Huffman, 2012; Vernooij et al., 2016; Zheng et al., 2010)		Huffman , 2012; van Vugt et al., 2013; Vernooij et al., 2016)			
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2013; Pinnock et al., 2017; Richard & Shea, 2011b; Richardso n et al., 2015; Sadler et al., 2017; Satink et al., 2016; Sattoe, 2015; Schulman- Green et al., 2016; Smith, Wallace, O'Dowd, & Fortin, 2016; Solomon et al., 2012; Spence Lasching er, Gilbert, Smith, & Leslie, 2010; Vaccaro &	et al., 2012; Song, Choi, Kim, Seo, & Lee, 2015; Vernooij et al., 2016; Wheelock et al., 2017; Zheng et al., 2010)	Minda, 2017; Zheng et al., 2010; Zwerink et al., 2014)						
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Huffman, 2012; van den Berg, Peters, Kraaijvel d, Gielissen, & Prins, 2013; van der Heide et al., 2014; van Vugt, de Wit, Cleijne, & Snoek, 2013; Vassilev et al., 2013; Vernooij, Willson, & Gagliardi, 2016; Wheelock, Miraldo, Thomson, Vincent, & Sevdalis, 2017; Zheng et								
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al., 2010; Zwerink et al., 2014)								
Professional Support	Emotional Support	Origin in SCT & CBT	Limit Illness Progression	Regulatory Function	Community Involvement	Improve Health	Lessens costs for health care systems	Performed deliberately
(Boger et al., 2015; Graham et al., 2016; Hutting et al., 2016; Jolly et al., 2016; Jones et al., 2013; Klippel et al., 2008; Laxy et al., 2014; Lenferink et al., 2017; Lim et al., 2015; Martin et al., 2010; Nolte & McKee, 2008; Norweg & Collins, 2013; Richard & Shea,	(AlMarsh edi et al., 2015; Bal et al., 2016; C. Barlow et al., 2010; Effing et al., 2007; Grijpma et al., 2016; Hutting et al., 2016; Jones et al., 2017, 2013; Kenning et al., 2010; Munce et al., 2016; Sadler et al., 2017; Satink et	(Brief et al., 2013; Burns et al., 2015; Ellis, J., Boger, E., Latter, S., Kennedy, A., Jones, F., Foster, C., & Demain, 2017; Ersser et al., 2007; Faithfull, Cockle-Hearne, & Khoo, 2011; Kennedy et al., 2013; Lau-Walker, 2009; Martin et al., 2010; Solberg et al., 2014;	(Ellis, J., Boger, E., Latter, S., Kennedy, A., Jones, F., Foster, C., & Demain, 2017; Kenning et al., 2015; Laxy et al., 2014; M.-C. Lee et al., 2016; Lenferink et al., 2017; Mittler et al., 2013; Munce et al., 2016; Nolte & McKee, 2008; Sadler et al., 2017; Savage et al., 2011; Song et al., 2015)	(Alvarado et al., 2017; Hutting et al., 2016; Mittler et al., 2013; Moriyama et al., 2009; Nolte & McKee, 2008; Sadler et al., 2017; Satink et al., 2016; Wheelock et al., 2017)	(Bal et al., 2016; Lau-Walker, 2009; Lim et al., 2015; Richard & Shea, 2011b; Satink et al., 2016; Savage et al., 2011; Schulman-Green et al., 2016)	(Boger et al., 2015; Hutting et al., 2016; Kenning et al., 2015; Nolte & McKee, 2008; Norman & Ryrrie, 2013; van Vugt et al., 2013; Wheelock et al., 2017)	(Ellis, J., Boger, E., Latter, S., Kennedy, A., Jones, F., Foster, C., & Demain, 2017; Foster et al., 2007; Kennedy et al., 2013; M.-C. Lee et al., 2016; Munce et al., 2016; Solberg et al., 2014; Vassilev et al., 2013)	(Ellis, J., Boger, E., Latter, S., Kennedy, A., Jones, F., Foster, C., & Demain, 2017; Graham et al., 2016; Nolte & McKee, 2008; Randall & Neubeck, 2016; Sadler et al., 2017; Satink et al., 2016)

2011b; Riekert et al., 2013; Sadler et al., 2017; Savage et al., 2011; Solberg et al., 2014; Vernooij et al., 2016)	al., 2016; van den Berg et al., 2013; Wheelock et al., 2017; Zwerink et al., 2014)	Richard & Shea, 2011a; Richardson et al., 2015; Sadler et al., 2017; van den Berg et al., 2013)						
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Table 3: Self-Help Characteristics

External Resource	Psychological Treatment	Unguided 'Pure'	Minimal Therapist Contact	Illness population	Flexible Application	Minimal Cost to Health Care	Origin in CBT	Professional Involvement 'Guided'
(Bachem & Maercker, 2016; Barth, Jacob, Daha, & Critchley, 2015; Blankers et al., 2011; Greenwell et al., 2015, 2016; P.	(Bachem & Maercker, 2016; Blankers et al., 2011; Greenwell et al., 2015, 2016; Herbst et al., 2012; Kaldo, Ramnerö, & Jernelöv, 2015; Ketelaar et al., 2014; Levy et al., 2016; Pratt et al., 2009; Rash	(Bachem & Maercker, 2016; Blankers et al., 2011; Greenwell et al., 2016; P. P. Hay et al., 2009; Khan et al., 2007b; Levy et al., 2016;	(Bachem & Maercker, 2016; Greenwell et al., 2016; P. P. Hay et al., 2009; Kaldo et al., 2015; Levy et al., 2016; Norman & Ryrie, 2013; Pratt	(Greenwell et al., 2016; P. P. Hay et al., 2009; Herbst et al., 2012; Norman & Ryrie, 2013; Pratt et al., 2009; Schneider et al., 2017; Varley et al., 2011; Wilson &	(Bachem & Maercker, 2016; Greenwell et al., 2015, 2016; P. P. Hay et al., 2009; Herbst et al., 2012; Rash & Petry, 2014; Thorsell et al., 2011)	(Bachem & Maercker, 2016; Greenwell et al., 2015, 2016; Pratt et al., 2009; Schneider et al., 2017; Thorsell et al., 2011)	(Blankers et al., 2011; P. P. Hay et al., 2009; Ketelaar et al., 2014; Khan et al., 2007b; Levy et al., 2016; Pratt et al., 2009)	(Bachem & Maercker, 2016; Greenwell et al., 2016; Khan et al., 2007b; Levy et al., 2016; Wilson & Zandberg, 2012)

Hay, Bacaltchuk, Stefano, & Kashyap, 2009; Khan, Bower, & Rogers, 2007b; Levy et al., 2016; Lintvedt et al., 2013; Norman & Ryrie, 2013; Pratt et al., 2009; Schneider et al., 2017; Varley et al., 2011; Wilson & Zandberg, 2012)	& Petry, 2014; Thorsell et al., 2011; Varley et al., 2011)	Pratt et al., 2009; Varley et al., 2011; Wilson & Zandberg, 2012)	et al., 2009; Varley et al., 2011)	Zandberg, 2012)				
Empower/ Motivate	Educate	Behaviour Change	Enhance Wellbeing	Action/Task	Develop Skills			
(Greenwell et al., 2016; Herbst et	(Hay et al., 2009; Ketelaar et al., 2014; Wilson &	(Norman & Ryrie, 2013; Pratt	(Ketelaar et al., 2014; Pratt	(Ketelaar et al., 2014; Pratt et al., 2009)	(Lintvedt et al., 2013; Wilson &			

al., 2012; Lintvedt et al., 2013; Pratt et al., 2009)	Zandberg, 2012)	et al., 2009)	et al., 2009)		Zandberg, 2012)
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Table 4: Self-Care Characteristics

Maintain Health Status	Action/Task	Perform Individually	Illness Population	Decision Making	Limit Illness Progression	Disease Prevention	Behaviour (Attitude)	Improve Health
(Albert, 2008a; Alligood, 2014; Barbaraneli et al., 2015; Baydemir et al., 2013; Berzins et al., 2009; Blickem et al., 2011; Cameron, Ski, & Thompson, 2012b; da Conceição, dos Santos,	(Aboagye, Karlsson, Hagberg, & Jensen, 2015; Albert, 2008a; Barbaranelli et al., 2015; Baydemir et al., 2013; Berzins et al., 2009; Blickem et al., 2011; Bonder & Dal Bello-Haas, 2008; Cameron et al., 2012b; Hudson et al., 2014,	(Alligood, 2014; Baydemir et al., 2013; Blickem et al., 2011; Cameron, Worrall-Carter, et al., 2010; Farmahini Farahani, Purfarzad, Ghorbani, Ghamari Zare, & Ghorbani, 2016; Høy et al., 2007; Lim et al., 2015; Lu et al., 2016;	(Barbaranelli et al., 2015; Berzins et al., 2009; da Conceição et al., 2015; Høy et al., 2007; Kang, Himmelfarb, et al., 2015; Köberich et al., 2015; Nolte & McKee, 2008; Peters-	(Albert, 2008a; Barbaraneli et al., 2015; Baydemir et al., 2013; da Conceição et al., 2015; Høy et al., 2007; Kang, Himmelfarb, et al., 2015; Nolte & McKee, 2008; Pereira & Santos,	(Baydemir et al., 2013; Berzins et al., 2009; Blickem et al., 2011; Cameron, Worrall-Carter, et al., 2010; Cameron et al., 2012b; da Conceição et al., 2015; Høy et al., 2007; Lim et al., 2015; Nolte & McKee, 2008; Norman & Ryrie, 2013)	(Baydemir et al., 2013; Blickem et al., 2011; Cameron, Worrall-Carter, et al., 2010; Cameron et al., 2012b; da Conceição et al., 2015; Høy et al., 2007; Cameron et al., 2012b; Hudson et al., 2014; Mawson et al., 2014b; Nolte & McKee, 2008; Norman & Ryrie, 2013)	(Barbaranelli et al., 2015; Cameron, Worrall-Carter, et al., 2010; Cameron et al., 2012b; da Conceição et al., 2015; Høy et al., 2007; Kang, Himmelfarb, et al., 2015; Peters-Klimm et al., 2013; Rhoades et al., 2016b; Strachan et al., 2014)	(Baydemir et al., 2013; Cameron, Worrall-Carter, et al., 2010; Cameron et al., 2012b; Høy et al., 2007; Nolte & McKee, 2008; Norman & Ryrie, 2013; Peters-Klimm et al., 2013; Richard & Shea, 2011a)

dos Santos, & da Cruz, 2015; Høy et al., 2007; Hudson, Bundy, Coventry, & Dickens, 2014; Kang, Himmelfarb, et al., 2015; Köberich, Lohrmann, Mittag, & Dassen, 2015; Lim et al., 2015; Manzini & Simonetti, 2009; Nolte & McKee, 2008; Ovayolu, Ovayolu, & Karadag,	2016; Kang, Himmelfarb, et al., 2015; Lim et al., 2015; Lu, Xu, Zhao, & Han, 2016; Manzini & Simonetti, 2009; Nolte & McKee, 2008; Rhoades et al., 2016b; Richard & Shea, 2011a; Rodríguez-Gázquez et al., 2012; Strachan et al., 2014; F. L. Wilson et al., 2008; Wu et al., 2007; Zrínyi & Zékányné, 2007)	Manzini & Simonetti, 2009; Mawson et al., 2014b; Nolte & McKee, 2008; Norman & Ryrie, 2013; Ovayolu et al., 2012; Richard & Shea, 2011a; Rodríguez-Gázquez et al., 2012; Ryan, Wilson, Taylor, & Greenfield, 2009; Strachan et al., 2014; Sundsli et al., 2013; F. L. Wilson et al., 2008)	Klimm et al., 2013; Richard & Shea, 2011a; Strachan et al., 2014; Vassilev et al., 2013; Wu et al., 2007)	2012; Richard & Shea, 2011a; Strachan et al., 2014; Zrínyi & Zékányné, 2007)				
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2012; Rhoades, Telliard, Thomas, & Barkin, 2016b; Richard & Shea, 2011a; Rodríguez -Gázquez et al., 2012; Strachan et al., 2014; Sundsli, Espnes, & Söderham n, 2013; F. L. Wilson et al., 2008; Wu et al., 2007; Zrínyi & Zékányné, 2007)								
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Activities of Daily Living	Regulatory Function	Professional Involvement	Community Involvement	Overall Population	Performed Deliberately	Non-Pharmacological	Performed for them	Pharmacological
(Bonder & Dal Bello-Haas, 2008; Cabrero-García & López-Pina, 2008; Donnelly & Karsten, 2017; Guiler, 2015; Jerez-Roig, Ferreira, de Araújo, & Lima, 2017; Munce et al., 2016)	(Alligood, 2014; Baydemir et al., 2013; Bonder & Dal Bello-Haas, 2008; Farmahini Farahani et al., 2016; Nolte & McKee, 2008; Rodríguez-Gázquez et al., 2012)	(Aboagye et al., 2015; Albert, 2008b; Høy et al., 2007; Nolte & McKee, 2008; Srinivas et al., 2017; Strachan et al., 2014)	(Baydemir et al., 2013; Nolte & McKee, 2008; Norman & Ryrrie, 2013; Strachan et al., 2014)	(Berzins et al., 2009; Mawson et al., 2014b; Nolte & McKee, 2008; Richard & Shea, 2011a)	(Alligood, 2014; Richard & Shea, 2011a; Rodríguez-Gázquez et al., 2012)	(Cameron et al., 2012b; Kang, Himmelfarb, et al., 2015; Peters-Klimm et al., 2013)	(Alligood, 2014; Nolte & McKee, 2008)	(Paul Jacob Robyn et al., 2011)